CanSupport Palliative Care Field Services

GUIDELINES

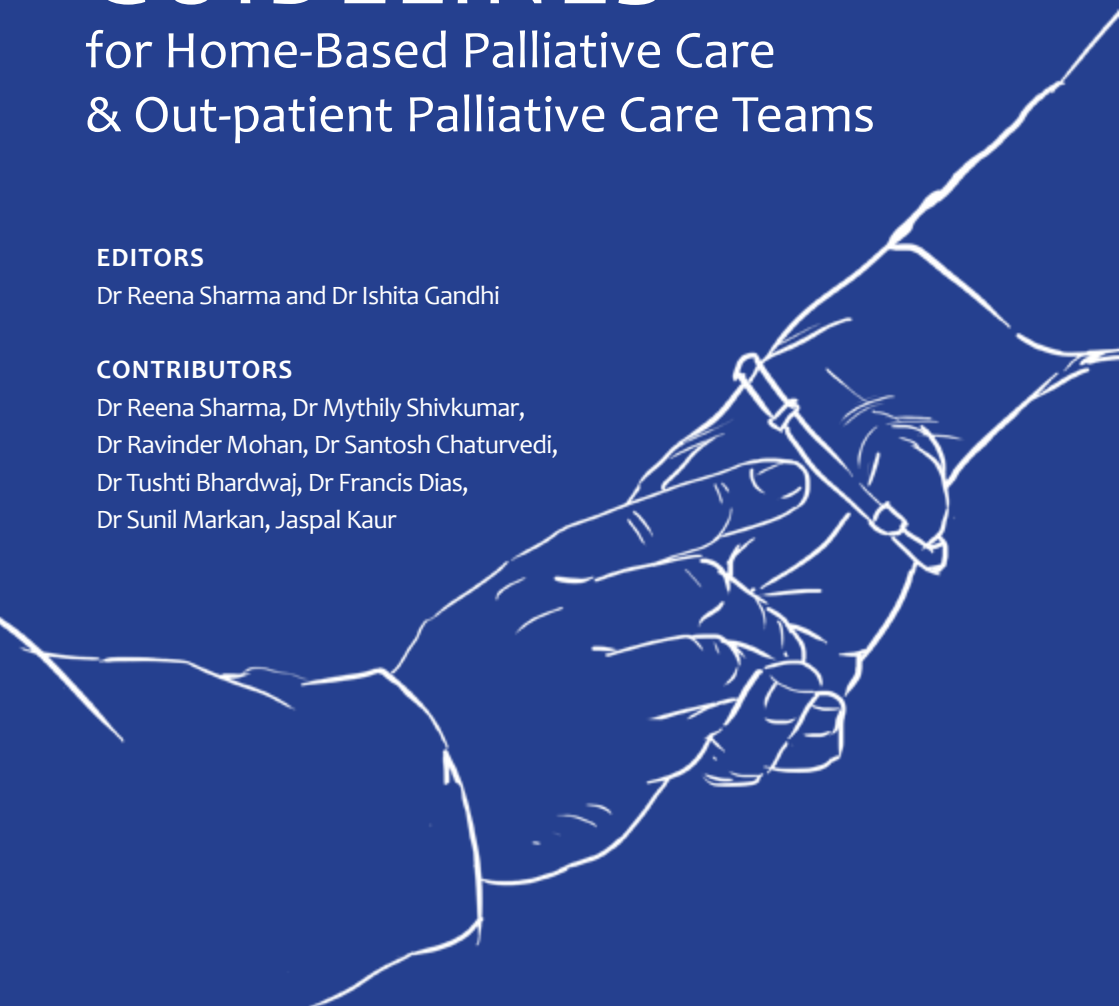
for Home-Based Palliative Care & Out-patient Palliative Care Teams

EDITORS

Dr Reena Sharma and Dr Ishita Gandhi

CONTRIBUTORS

Dr Reena Sharma, Dr Mythily Shivkumar, Dr Ravinder Mohan, Dr Santosh Chaturvedi, Dr Tushti Bhardwaj, Dr Francis Dias, Dr Sunil Markan, Jaspal Kaur



About CanSupport
CanSupport runs India's largest free home-based palliative care programme. At any given time, our palliative care teams are caring for 2600 cancer patients and their families. We also run out-patient clinics, day care centers and training programmes.

Book Design: Tinatoons

Website: www.cansupport.org
Email: info@cansupport.org
Address: A-2, Gulmohar Park, (Opp Kamla Nehru College), New Delhi - 110049

CanSupport Helpline Numbers: 011-41010539 / 91-9899011212, Monday to Saturday - 9 am to 6 pm
Saath Saath National Palliative Care Helpline: 1800-202-7777, Monday to Saturday - 10 am to 6 pm

CanSupport's Guidelines for Home-Based Palliative Care
and Palliative Out-patient Clinics
Specialised Guidelines for Homecare, Symptom Control, Psychosocial Support,
Bereavement Support

EDITORS
Dr Reena Sharma and Dr Ishita Gandhi

CONTRIBUTORS
Dr Reena Sharma, Dr Mythily Shivkumar, Dr Ravinder Mohan,
Dr Santosh Chaturvedi, Dr Tushti Bhardwaj, Dr Francis Dias,
Dr Sunil Markan, Jaspal Kaur

The contents of this book outline the current practice of the palliative care teams at CanSupport.

They are written specifically for doctors, nurses, counselors and other members of the multidisciplinary team addressing symptom and psychosocial problems of patients registered in CanSupport's homecare program and out-patient clinics.

The guidelines may not necessarily apply to units outside CanSupport.

The document was written and reviewed internally by members of CanSupport's homecare program.

Many of the recommendations apply only to those with specific training and expertise in Palliative Care.

"The use of drugs beyond license in palliative care and pain management practice is currently both necessary and common and it should be seen as a legitimate aspect of clinical practice" Many of the drugs listed in these guidelines are recommended for unlicensed indications, at unlicensed doses and by unlicensed routes.

(Bennett M, Simpson K. The use of drugs beyond licence in palliative care and pain management.Palliat Med. 2002; 16:137)

Foreword

This is a book that was waiting to be written. It is the culmination of more than twenty five years of experience and exemplary service rendered by CanSupport's trained and talented palliative care teams.

From its inception, CanSupport had a mission to offer comfort, support and expert care to those living with advanced cancers in their homes. Since the focus was on the least privileged, the service was free of charge. Moreover, help in kind, including rehabilitative care, was provided as and when needed. What I can justly claim has also been, and continues to be, the hallmark of CanSupport is its commitment to psychosocial and spiritual care. Every patient and family member that CanSupport has ever cared for has had access to this vital support which continues throughout the period of bereavement.

The titles of the chapters of this book are self explanatory and the material under each serve as an essential learning tool for palliative care teams , especially counsellors, who wish to improve their skills. The case studies are rooted in the culture and traditions of India and can therefore be easily used and related to.

I applaud and thank all those who contributed to this endeavour. It is truly a labour of love which is rooted in the firm belief that attending to feelings and perceptions is as important for the human being as responding to physical needs. It is a lesson my own experience with cancer taught me well.

Harmala Gupta

Founder President, CanSupport
New Delhi
March 2023

Acknowledgements

In producing the present book, we are fortunate to count on the active help and encouragement of friends and collaborators whose advice and criticism was invaluable to us. We take this opportunity to express our gratitude to the following people for their kind support.

We are grateful to Ms. Harmala Gupta, whose consistent inspiration gave us strength and motivation to write this book.

Dr. Rakesh Garg, Professor Department of Onco-Anaesthesia & Palliative Medicine Dr BRAIRCH, AIIMS, New Delhi for his patient deliberation and guidance on the symptom management in palliative care.

Dr. Sandhya Gupta, Health Consultant & Lifestyle Coach, Formerly Principal (Acting) & Associate Professor College of Nursing AIIMS, New Delhi for her invaluable inputs on nursing care in Palliative patients.

Dr. Santosh Chaturvedi, Former Dean & Senior Professor of Psychiatry, National Institute of Mental Health & Neurosciences, Bangalore, for his important suggestions for overall format of the counselling topics and his advice to incorporate praxis of CanSupport.

Dr. Tushti Bhardwaj, Professor, Social works Department, Dr. for her advice and tireless editing work of the form and content of counselling part.

Dr. Rangaswamy Srinivasa Murthy, Retd. Professor of Psychiatry, National Institute of Mental Health & Neurosciences, Bangalore, for his encouragement to incorporate experiential learning of CanSupport especially in providing spiritual care to the patients and care givers.

Ms. Areet Narang Bastola, Director, Chaitanya Institute for Mental Health, Nepal, for her core contribution in psychological distress part of the book.

Ms. Rajni B Arora, volunteer, member of editorial and events committee, CanSupport, for her unwavering support in content and copy editing.

There are too many to name here, Dr.Ambika Rajvanshi (CEO CANSUPPORT), MS. Savita Luka (Head Home Care), Dr. Reena Sharma (Medical Director), Dr. Ravinder Mohan (Director NDPS) Ms. Jaspal Kaur (Counselling Director), Ms. Anu Paul (Deputy Director Counselling), Ms. Pallika (Senior Counsellor), Mr. Narinder Gautam (Senior Counsellor), Mr. Anil Sharma (Senior Counsellor) Ms. Mausumi Bhansali (Senior Counsellor), without their valuable contribution this work would not have been possible.

Abbreviations

ACE	Angiotensin converting enzyme
bd	Twice daily
BBB	Blood brain barrier
BTP	Breakthrough pain
CISC	Clean Intermittent Self-Catheterization
CSCI	Continuous subcutaneous infusion
GIT	Gastrointestinal tract
hs	At night
IASP	International Association for the Study of Pain
IM	Intramuscular
IR	Immediate release
IV	Intravenous
KPS	Karnofsky's Performance Score
MBO	Malignant bowel obstruction
M3G	Morphine-3-glucoronide
M6G	Morphine-6-glucoronide
MLD	manual lymphatic drainage
MUI	Mixed urinary incontinence
NG	Nasogastric
NRS	Numeric Rating Scale
NSAIDs	Non-steroidal anti-inflammatory drugs
OAB	Overactive bladder
od	Once daily
OFI	Overflow incontinence
OTFC	Oral Transmucosal Fentanyl Citrate
PEG	Percutaneous endoscopic gastrostomy
PPI	Proton pump inhibitors
PO	Orally
qid	Four times a day
SC	Subcutaneous
SCC	Spinal cord compression
SLD	simple lymphatic drainage
SR	Sustained release
SUI	Stress urinary incontinence
SVCO	Superior Vena Cava Obstruction
tds	Three times a day
TD	Transdermal
tds	three times a day
UI	Urinary incontinence
UUI	Urge urinary incontinence
UTI	Urinary tract infection
VAS	Visual Analog Scale

Contents

Pain Assessment and Management

A. PAIN ASSESSMENT

These guidelines are for management of pain in adult patients suffering from a serious life-limiting condition like cancer.

INTRODUCTION

Definition of Pain

According to the International Association for the Study of Pain (IASP) definition of pain(revised definition): "Pain is an unpleasant sensory and emotional experience associated with or resembling that associated with actual or potential tissue damage or described in terms of such damage".

In simpler terms: "Pain is what the patient says hurts". Pain is a subjective experience and is based on the patient's description.

Chronic Pain

Chronic pain is defined as 'pain which persists beyond the usual course of healing or is associated with chronic pathological illness which causes continuous pain or pain which recurs at intervals for months of years

Types of Pain

Nociceptive pain- caused by ongoing tissue damage and may be somatic (in bone, muscle) or visceral (in hollow viscous, solid organ).
Neuropathic pain- caused by nerve damage in central or peripheral nervous system.

Breakthrough Pain

"Breakthrough pain (BTP) is a transient increase in pain intensity that occurs either spontaneously or in relation to a specific predictable or unpredictable trigger, despite relatively stable and adequately controlled background pain."

Total Pain

Total pain refers to the physical, psychological, social and spiritual factors that influence pain perception and experience. Cancer patients may not have adequate pain relief until all components are addressed.

Prevalence of Cancer Pain

Estimated prevalence of cancer pain according to stage of disease:

After curative treatment	- 39.3%
During anti-cancer treatment	- 55%
Advanced disease	- 66.4%

Causes of Cancer Pain

Cancer pain occurs due to nociceptive or neuropathic damage or both (mixed pain) and may be a result of the disease or its treatment. Mixed cancer pain results as on the one hand tumor growth induces tissue damage and the release of various inflammatory mediators while the compression, infiltration, or obstruction of tissue and injury to nerve fibers result in neuropathic pain.

Disease-related: direct invasion and tissue destruction by cancer, pressure on surrounding structures.

Treatment-related: post-surgery, chemotherapy neuropathy, radiation-induced mucositis.

In addition to physical causes cancer pain is also affected by psychosocial and spiritual factors and this needs to be considered in assessment and management of pain.

ASSESSMENT

Global assessment of the Person should Guide Treatment

- The first step in pain management is assessment of the patient.
- Pain is a subjective measure so patient self-report is most important. All patients should be screened for pain on each OPD/home visit.
- An initial comprehensive assessment should be done including history, physical examination, psychosocial assessment and measurement of pain severity using a pain measurement tool like numeric rating scale (NRS- Fig 2.1a) or visual acuity scale (VAS- Figure 2.1b). Ongoing reassessment should be carried out on subsequent visits to ensure appropriate treatment, management of side effects and good pain relief.

OPQRSTUV Assessment Method[6] (Table 1) may be used to do a comprehensive pain assessment.

Patients may have more than one pain and each pain should be assessed separately. The type of pain should be determined i.e. whether the pain is nociceptive or neuropathic.

Psychosocial distress may be a cause of increased/uncontrolled pain and should be assessed.

Table 1

OPQRSTUV PAIN ASSESSMENT METHOD[6]

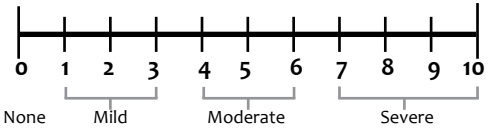
(Adapted from Fraser Health Authority "Symptom Assessment Acronym "OPQRSTUV")

Onset Provoking/ Palliating	When did it begin? How long does it last? How often does it occur? What brings it on? What makes it better? What makes it worse?
Quality Region/ Radiation	What does it feel like? Can you describe it? Where is it? Does it spread anywhere?
Severity	What is the intensity of this symptom (On a scale of 0 to 10 with 0 being none and 10 being worst possible)? Right now? At best? At worst? On average? How bothered are you by this symptom? Are there any other symptom(s) that accompany this symptom?
Treatment	What medications and treatments are you currently using? How effective are these? Do you have any side effects from the medications and treatments? What medications and treatments have you used in the past?
Understanding/ Impact on You	What do you believe is causing this symptom? How is this symptom affecting you and / or your family?
Values	What is your goal for this symptom? What is your comfort goal or acceptable level for this symptom (On a scale of 0 to 10 with 0 being none and 10 being worst possible)? Are there any other views or feelings about this symptom that are important to you or your family?

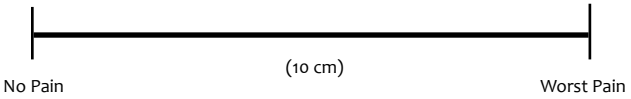
Figure 2.1

TOOLS TO MEASURE PAIN INTENSITY

i. Numeric Rating scale



ii. Visual Analogue Scale



Pain Assessment in Elderly/Cognitively Impaired

Self-reporting of pain is difficult in elderly patients with poor communication skills or cognitively impaired patients. Observation scales are available but none is validated in different languages. In these groups observation of pain-related behavior like facial expression, body movements, verbalization or vocalizations, changes in interpersonal interactions and changes in routine activity could be used to assess presence of pain.

Behavioral observation-based assessment

- Facial expressions- frowning, grimacing
- Verbalizations/vocalizations- sighing, moaning
- Body movements- rigid, tense, guarding, rocking
- Changes in interpersonal interactions
- Changes in activity patterns: sleep, appetite
- Mental status change: crying, irritability

Physiological Indicators

- Increased heart rate
- Increased blood pressure
- Increased breathing rate
- Diaphoresis
- Pupil dilatation

B. MANAGEMENT OF PAIN

The aim is to relieve pain to a level that leads to an acceptable quality of life and this is a requirement of cancer and other palliative care patients at all stages of their disease not just right at the end.

A patient's total pain should be managed for good pain relief.

In addition to pharmacological management, psychosocial, emotional and spiritual issues should also be addressed. Very anxious or depressed patients may also need pharmacological therapy in addition to analgesics.

Integration of Cancer Pain Management with Cancer Treatment

Cancer pain management should be integrated with cancer treatment even when disease is not terminal. The patient and caregiver should be given an explanation

of causes of pain. Adherence to analgesics will improve if patient understands the reasons for the treatment. Analgesics can be taken along with cancer treatment.

Pharmacological Management

WHO ANALGESIC LADDER

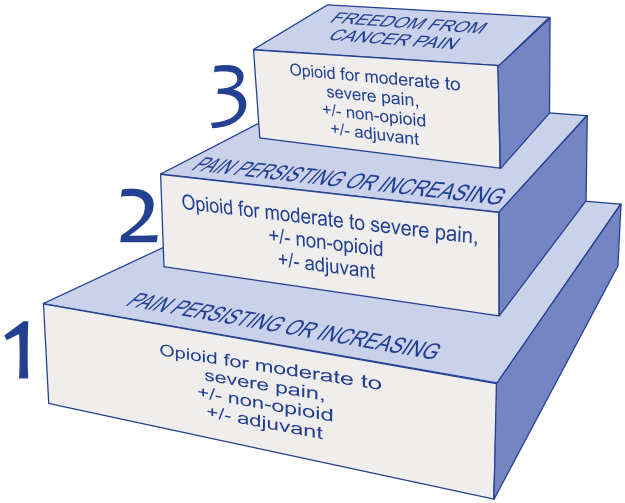
Managing pain according to WHO Analgesic Ladder results in good pain relief for majority of cancer patients.

PRINCIPLES FOR ADMINISTRATION OF ANALGESIC MEDICINE

By mouth: Analgesics should be given orally as far as possible.
By the clock: Analgesic dose should be given at fixed intervals of time. The dose should be increased gradually until the patient is comfortable. The next dose should be given before the effect of the previous dose has worn off.
For the individual: Comprehensive pain assessment along with site and type of pain to be determined before deciding on medication. Analgesic doses should be increased or decreased according to pain assessment on subsequent visits.
By the ladder: The WHO analgesic ladder should be used as a guide for prescribing analgesics according to pain severity.
Attention to detail: The patient and caregivers should be educated about side effects of medication and their management

Figure 2.2

THE WHO ANALGESIC LADDER



STEP 1: MILD PAIN (NRS ≤3)	PAIN PERSISTING OR INCREASING
Non-opioids ± adjuvant analgesic	Patients with mild pain should receive either a NSAID or paracetamol ± adjuvant at licensed doses. The choice should be based on a risk/benefit analysis for each individual patient.
Drug options paracetamol non-steroidal anti-inflammatory drugs (NSAIDs: Non-selective COX inhibitors ibuprofen, diclofenac, ketorolac, naproxen; Selective COX-2 Inhibitors- celecoxib, etoricoxib) ± adjuvant analgesics	Patients receiving a NSAID who are at risk of gastrointestinal side effects* should be prescribed Proton pump inhibitors e.g. Omeprazole 20mg od or Pantoprazole 40mg od or H2 antagonist Ranitidine 150mg bd

STEP 2: MILD TO MODERATE PAIN (NRS 4-6)	PAIN PERSISTING OR INCREASING
Opioid for mild to moderate pain non-opioid ± adjuvant analgesics	Patients with mild to moderate pain should receive tramadol or codeine ± NSAID ±Adjuvant.
Drug options codeine tramadol ± non-opioids (paracetamol/NSAIDs) ± adjuvants analgesics	If the effect of an opioid for mild to moderate pain at optimum dose is not adequate, do not change to another opioid for mild to moderate pain. Move to step 3 of the analgesic ladder. Compound analgesics containing sub-therapeutic doses of opioids should not be used for pain control in patients with cancer (see chapter 2)

STEP 3: MODERATE TO SEVERE PAIN (NRS 7-10)	FREEDOM FROM CANCER PAIN
Opioid for moderate to severe pain ± non-opioid ± adjuvant analgesics	morphine (if available) should be used as the first line drug of choice to treat moderate to severe pain in patients with cancer
Drug options morphine (oral/parenteral) ± step 1 non-opioids (paracetamol/NSAIDs) ± adjuvant analgesics	The oral route is the recommended route of First line administration and should be used where possible.
Alternatives to morphine fentanyl TD buprenorphine TD Tapentadol Methadone	A trial of alternative opioids should be considered for moderate to severe pain where dose titration is limited by lack of analgesia and/or side effects of morphine

REFERENCES

1. Raja SN, Carr DB, Cohen M, et al. The revised International Association for the Study of Pain definition of pain: concepts, challenges, and compromises. Pain. 2020;161(9):1976-1982.
2. Bonica, J.J. (1990). Definitions and taxonomy of pain. In J.J. Bonica (ed.) The Management of Pain, pp. 18–27. Philadelphia, PA: Lea and Febiger.
3. Davies AN, Dickman A, Reid C, Stevens AM, Zeppetella G. The management of cancer-related breakthrough pain: recommendations of a task group of the Science Committee of Association for Palliative Medicine of Great Britain and Ireland. Eur J Pain. 2009;13:331-8
4. van den Beuken-van Everdingen MH, Hoschtenbach LM, Joosten EA, Tjan-Heijnan VC, Janssen DJ. Update on prevalence of pain in patients with cancer: Systematic review and meta-analysis.J Pain Sympt Management. 2016; 51(6): 1070-1090
5. Who guidelines for the pharmacological and radiotherapeutic management of cancer pain in adults and adolescents.2018
6. Fraser Health Authority [Internet].Symptom Assessment Acronym "OPQRSTUV". Retrieved from https://www.fraserhealth.ca/-/media/Symptom assessment revised_Sept09.pdf (accessed 08 June 2019)
7. Rayment C, Bennett MI. Definition and assessment of chronic pain in advanced cancer. In Hanks G et al (eds). Oxford Textbook of Palliative Medicine 5th ed. Oxford. OUP.p 519-24
8. Fallon M, Giusti R, Aielli F, Hoskin P, Rolke R, Sharma M, Ripamonti CI, ESMO Guidelines Committee, Management of cancer pain in adult patients: ESMO Clinical Practice Guidelines, Annals of Oncology, 2018; 29 Suppl 4: iv166–iv191.
9. Stockler M et al. Paracetamol improves pain and wellbeing in people with advanced cancer already receiving a strong opioid regimen: a randomized, double-blind, placebo-controlled, cross-over trial. Jour of CinicalOnclogy.2004; 22:3389-94.
10. Twycross, R., Wilcock, A., Howard, P. Palliative Care Formulary 5+. Nottingham. palliativedrugs.com; 2016. Drug Monogram 5- Analgesics. (pp. 384-581)

Analgesics for Pain Management- Non-Opioids

NON-OPIOIDS

These drugs are the first to be prescribed to patients with mild pain i.e. step 1 of WHO ladder. They may also be prescribed with mild opioids on step 2 of the ladder or with strong opioids on step 3 of the ladder.

a. Paracetamol

- Opioid-sparing effect (1/3 patients)

Onset of action- 15-30min PO, 5-10 min IV duration – 4-6hrs

Dose- Appropriate for weight - 10-15mg/kg/dose

Maximum dose/24hrs - 4g in>50kg adults and children

3g in <50kg adults & children with risk factors

2g in adult patients with hepatic dysfunction (cirrhosis)

Risk of Hepatotoxicity: Unintentional overdose of paracetamol can result in hepatotoxicity so the maximum recommended dose should never be exceeded. The dose should be appropriate for weight and should be decreased in the presence of risk factors e.g. old age, poor nutritional status, anorexia, chronic alcohol abuse.

Drug Interactions

- Concurrent use of glucoronidation inhibitors and/or CYP2E-1 inducing drugs e.g. phenobarbitone and probably isoniazid may increase risk of paracetamol toxicity
- In patients taking Vitamin K Antagonists (warfarin, acenocoumarol) concurrent use of paracetamol may cause a dose dependent increase in INR. It does not occur if paracetamol dose <2g/week.

b. NSAIDs

Non-selective NSAIDs- Ibuprofen, Diclofenac, Naproxen, Ketorolac (Referred to as NSAIDs).

Selective Cox-2 Inhibitors- Celecoxib, Etoricoxib (Referred to as Cox-2 Inhibitors).

COMMONLY USED NSAIDS

DRUG	USUAL ORAL DOSE	COMMENTS
NON-SELECTIVE NSAIDS		
Ibuprofen	400mg tds Maximum (max) dose: 1200mg/day	Available in combination with paracetamol (Ibuprofen 400mg + Paracetamol 325mg) Fewer side-effects than other NSAIDs but weaker anti-inflammatory properties
Diclofenac Naproxen	50 mg tds, 75 mg bd Maxdose: 150mg/day 250-500 mg bd	Can be given subcutaneously Fewer GI side effects Relatively lower risk of major cardiovascular event
Ketorolac	10 mg 6 hrly (max dose: 40 mg/day)	higher analgesic/anti-inflammatory ratio, can be given subcutaneously
SELECTIVE COX-2 INHIBITORS		
Celecoxib Etoricoxib	100 – 200mg bd 60 – 90mg od or bd Max dose: 180mg/day	Fewer GI side effects No platelet dysfunction Fewer GI side effects No platelet dysfunction

All patients should take lowest effective dose of NSAIDs or COX-2 inhibitors for the shortest time necessary to control symptoms. The need for long term treatment should be reviewed periodically.

Prescribing should be based on the safety profiles of individual NSAIDs or COX-2 inhibitors and on individual patient risk profiles (e.g. gastrointestinal and cardiovascular – see below).

Concomitant aspirin (and possibly other anti-platelet drugs) greatly increase the gastrointestinal risks of NSAIDs and severely reduce any gastrointestinal safety advantages of COX-2 inhibitors. Aspirin should only be co-prescribed if absolutely necessary.

The choice of NSAID is based on best clinical judgment, taking into account efficacy, safety, cost, availability, route of administration, and drug interactions.

Diclofenac and naproxen both have a good toxicity profile, in particular less GI toxicity than many other NSAIDs.

Use with great caution in patients at risk of renal impairment.

COX-2 inhibitors should be considered in those patients with low platelet counts, history of bleeding or who have a past history or significant risk of GI toxicity, although they are not without risk themselves.

Adverse Effects

i. Blood- Platelet dysfunction and increased bleeding time- not seen with COX-2 inhibitors
ii. iGastrointestinal- Peptic ulcer, bleeding, perforation
    Small bowel stricture, bleeding, perforation
    Protein-losing enteropathy
iii. Kidney- Salt & water retention, acute or acute-on-chronic renal failure
iv. Cardiovascular- Thrombosis e.g. myocardial infarction, stroke- relatively greater risk with diclofenac and COX-2 inhibitors
v. Lungs- Bronchospasm (Asthma)

Risk Factors for NSAID-related Upper GI Complications

i. Elderly >65yrs
ii. Peptic ulcer or GI bleeding in last one year
iii. Long term use of maximum recommended dose of NSAID
iv. Concurrent use of aspirin, steroids or anticoagulants
v. Platelet count <50 x 109/L
vi. Concurrent use of serotonin reuptake inhibitor

Proton Pump Inhibitors (PPIs) and H2 antagonists are effective in preventing chronic NSAID-related peptic ulcers10 and should be added when an NSAID is prescribed.

Contraindications to NSAIDs

i. Hypersensitivity to NSAIDs
ii. Active GI ulceration, bleeding, perforation, inflammation
iii. Bleeding from malignant wound or tumor (Cox-2 inhibitors may be prescribed)
iv. Patient on anticoagulant drugs as increased chance of bleeding
v. Severe heart failure
vi. Severe renal impairment (creatinine clearance <30ml/min), deteriorating renal function, hyperkalemia (>5mmol/L)
vii. Active liver disease or moderate-severe hepatic impairment

Choosing an NSAID

First Choice
Ibuprofen ≤1200gm/24hrs- low risk of GI toxicity and major cardiovascular event
In patients at high risk of upper GI complications
Diclofenac and COX-2 inhibitors
In patients at high risk of major cardiovascular event
Naproxen 1gm/24hrs
In patients with low platelet counts or history or risk of bleeding
COX-2 inhibitors

REFERENCES

1. Fallon M, Giusti R, Aielli F, Hoskin P, Rolke R, Sharma M, Ripamonti CI, ESMO Guidelines Committee, Management of cancer pain in adult patients: ESMO Clinical Practice Guidelines, Annals of Oncology, 2018; 29 Suppl 4: iv166–iv191.
2. Stockler M et al. Paracetamol improves pain and wellbeing in people with advanced cancer already receiving a strong opioid regimen: a randomized, double-blind, placebo-controlled, cross-over trial. Jour of CinicalOnclogy.2004; 22:3389-94.
3. Twycross, R., Wilcock, A., Howard, P. Palliative Care Formulary 5+. Nottingham. palliativedrugs.com; 2016. Drug Monogram 5- Analgesics. (pp. 384-581).
4. Sjogren P, Elsner F, Kaasa S. In Hanks G et al (eds). Oxford Textbook of Palliative Medicine 5th ed. Oxford. OUP.pp 567-76.
5. Rostom A et al. Prevention of NSAID-induced gastroduodenal ulcers. Cochrane Database of Systematic Reviews.2002; 4: CD002296.

Analgesics for Pain Management- Opioids

A. Weak Opioids

Weak opioids are prescribed on step 2 of WHO ladder for moderate pain.
Tramadol, Codiene.

CODIENE

Codiene is a naturally occurring opium alkaloid about one-tenth as potent as morphine. It is metabolized mainly into codiene-6-glucoronide (80%). A small fraction (<10%) is also metabolized into morphine by the hepatic CYP2D6 enzyme and this chiefly contributes to its analgesic effect. However due to genetic polymorphism there is wide inter-individual variation in codiene metabolism and poor metabolizers have little or no analgesia with this drug.

It is a weak opioid and is used in step 2 of the analgesic ladder.
Dose: 30-60mg 4hourly. Maximum dose is 360mg/24hrs.
Adverse effects are similar to those of strong opioids.

TRAMADOL

Tramadol is a synthetic, centrally acting opioid. In addition to being a mu agonist it is also a serotonin and nor-adrenaline re-uptake inhibitor and this explains its effect on neuropathic pain. It is one-fourth to one-fifth as potent as morphine.

It is a weak opioid used on step 2 of the analgesic ladder.
Dose: 50-100mg 6-8hourly. Maximum dose is 400mg/24hrs; It can be given orally and parenterally (IV, IM, SC).

ADVERSE EFFECT	MANAGEMENT	COMMENT
Nausea & Vomiting	Haloperidol 1.5mg bd or Metoclopramide 10mg tds	Usually transient and improves in 5-7 days. If persistent change to alternate opioid
Sedation	Reduce dose or skip dose of oral opioid till drowsiness decreases	Look for other factors if no response to decreased dose

Constipation	Laxatives should be prescribed for all patients started on strong opioids	Is usually persistent
Myoclonus	Benzodiazepine e.g. Lorazepam 0.5-1mg stat & p.r.n; Reduce dose of opioid; Switch to alternate opioid	Usually seen with high doses of IV or spinal morphine
Pruritis	Antihistamine e.g. Cetrizine 5-10mg od; If persistent switch to alternate opioid	May be self-limiting
Delirium and/or hallucinations	Reduce opioid dose; prescribe anti-psychotic e.g. haloperidol 0.5mg stat & q2h p.r.n.; switch to alternate opioid	Some patients have intractable delirium and/or hallucinations with one opioid and not with alternative opioid

Precautions: Care should be taken when prescribing other drugs which interfere with serotonin re-uptake e.g antidepressants as serotonin toxicity may occur.
Adverse effects: Similar to other opioids but it usually causes less constipation than morphine and codiene. (See: Opioid adverse effects).

Availability
Capsule - 50mg, 100mg; Combination of: Tramadol 37.5mg +Paracetamol 325mg; Tramadol 50mg+Paracetamol 500mg
Injection - 50mg/ml, 2ml

B. STRONG OPIOIDS
Strong opioids are recommended for moderate to severe pain (Step 3 of WHO ladder). If the patient is on a weak opioid that is discontinued before starting a strong opioid. Available strong opioids in India: Morphine, Fentanyl, Buprenorphine, Tapentadol and Methadone

When strong opioids are carefully titrated against a patient's pain there are absolutely no contraindications to their use in palliative care.

Morphine is the strong opioid of choice for moderate to severe pain in cancer patients.

Opioid Adverse Effects

Common: Nausea and vomiting, drowsiness, constipation, dry mouth
Less common: Neurotoxicity (hyperalgesia, allodynia, myoclonus), sweating, pruritis, urinary retention

Management of Opioid Adverse Effects

OPIOID SWITCHING ('ROTATION')

- Reasons for opioid switching:
- Intolerable side effects e.g. persistent nausea and vomiting, persisting drowsiness, neurotoxicity (hallucinations, myoclonus), severe constipation, urinary retention
- Poorly controlled pain
- Patients who are unable to take their medication orally and where a subcutaneous infusion of morphine is inappropriate (e.g. long term use)
- Toxicity due to renal impairment

STRONG OPIOIDS - STARTING DOSE

DRUG	STARTING DOSE	COMMENTS
Morphine	In opioid naïve patient starting dose: 5mg q4h PO If switching from weak opioid start equivalent dose If inadequate pain relief dose increased by 50-100% of 4hrly dose	Morphine dose is titrated according to a patient's pain There is no ceiling to the analgesic effect of morphine so the dose can be increased till the patient has relief Addiction is rare in patients with cancer pain
Fentanyl Patch	In opioid naïve patients starting dose: 12.5mcg/hr TD If switching from oral morphine or other opioid then start equivalent dose	
Buprenorphine Patch	In opioid naïve patients starting dose 10mcg/hr TD	Usually started when patient intolerant to morphine side effects, poor adherence to oral medication or in renal failure

		Also available as 5mcg/hr patch which may be given for moderate pain instead of weak oopioid
Tapentadol	In opioid naïve or moderate pain starting dose 50mg q4-6h If switching from oral morphine or other strong opioid start equivalent dose	Side effects are as in other strong opioids It is about 3 times less potent than morphine
Methadone	Methadone should be started in hospital as patient needs to be observed carefully. -Prescribing as first line strong opioid: start 2.5mg (in elderly 1-2mg) q12h and q3h prn. Increase dose weekly according to prn doses given -Switching from morphine to methadone preferably done in hospital- Morphine should be stopped abruptly. -Switching from IR morphine first dose of methadone given >2hr – 4hr after lasr morphine dose. Switching from MR morphine first dose of morphine given >6hr (pain present) or 12hr (pain-free) after last MR morphine dose	Usually used in patients who respond poorly to morphine or as an alternative in patients intolerant to other strong opioids

I. MORPHINE

Morphine is the main naturally occurring alkaloid of opium. It is the opioid of first choice in cancer patients with moderate to severe pain. It is metabolized mainly in the liver to morphine-6-glucoronide (M6G) and morphine-3-glucoronide (M3G). The active metabolite, M6G, accounts for 10-15% of metabolites and is 100 times more potent than morphine but availability in the CNS is less due to poor penetration of the blood brain barrier (BBB). The inactive metabolite M3G accounts for approximately 80% of metabolites and probably accounts for some of the central side effects of morphine

like drowsiness, nausea, vomiting, respiratory depression and coma. In severe liver impairment morphine half-life may be increased and morphine dose may need to be decreased or given less frequently (6hrly or 8hrly).

- Oral morphine is the opioid of first choice in patients with moderate to severe pain
- There is no ceiling effect with respect to analgesia and dose required to achieve pain relief may vary 1000 fold. Inter-individual variation in first pass hepatic metabolism accounts, in part, for this variation.
- Systemic availability of oral morphine is poor - 35% (range 16-68%) which contributes to the occasional unpredictable onset of action and inter-individual variability in dose requirement and response.
- The majority of patients will be controlled on a dose of morphine of ≥30mg 4 hourly (or equivalent).
- Not all pain is totally morphine sensitive (e.g. neuropathic pain, bony pain).
- Not all individuals benefit from morphine- some individuals either do not achieve adequate pain relief or they develop dose limiting side effects.
- Clinical experience has shown that excessive sedation and respiratory depression does not occur when the drug is titrated correctly for therapeutic indications.
- Patients' driving ability is not significantly impaired when on a stable dose.
- Initiation of morphine should not be delayed by anxiety about tolerance.
- Most patients on morphine whose pain resolves can reduce the dose and discontinue it without difficulty.
- Patients started on morphine may become physically dependent on it and should be reassured that they will not become psychologically dependent.

MORPHINE PREPARATIONS

Tablet: immediate release (IR) 10mg, 30mg, 60mg.
Sustained release (SR) 10mg, 30mg, 60mg
Injection: 10mg/ml, 15mg/ml
Onset of action: IR tablet- 20-30minutes
SR tablet- 60 minutes
Duration of action: IR tablets- 3-6hrs
SR tablets- 12hrs

Side Effects (See *Opioid adverse effects*)

PRESCRIBING ORAL MORPHINE

- Use IR preparations to titrate. If a patient is already on maximum dose of a weak opioid stop the weak opioid and start morphine at dose of 10mg 4 hrly. If a patient is opioid naive, start at 5mg 4 hrly.
- In the elderly consider starting at 5mg 4/6hrly or 8hrly in patients above 80yrs.
- For BTP prescribe p.r.n. IR morphine at 50-100% of the 4 hrly dose, given as often as required (up to hourly).
- There is no limit to the number of extra doses that can be administered. Review daily and take the number of breakthrough doses into account when adjusting the total daily dose.
- Increase the 4 hrly dose by approximately 30-50% every 24 hours until pain is controlled. Suggested increments are as follows: 10-15-20-30-40-60-90-120mg.
- It is convenient to give a double dose of morphine at bedtime. This approach results in less pain during the night, better sleep and no increase in early morning pain.
- Patients and caregivers should be educated about morphine, its side effects and their management and the rarity of psychological dependence.
- An anti-emetic, haloperidol 1.5mg stat and at bedtime (or Metoclopramide 10mg stat and at bedtime), should be prescribed for p.r.n. use during the first week or regularly if the patient had nausea with a weak opioid.
- A laxative should be prescribed routinely unless there is a reason for not doing so e.g. a patient with an ileostomy.
- If a patient has increased drowsiness in first 1-2 days one or two doses may be missed until drowsiness decreases.
- Once the pain is adequately controlled on 4 hrly IR preparations, convert to an SR morphine preparation. To convert the dose add up the total morphine requirement including both regular and breakthrough doses in the previous 24 hours, divide by 2 or 3 and prescribe at this dose to be given 12hrly or 8hrly daily. IR morphine is given for breakthrough pain and the dose is 1/6th of the 24hr dose.
- If a patient is already on an SR morphine preparation and is in severe pain, dose may be re-titrated by converting back to an IR preparation given 4 hrly with dose increases as above until pain is controlled.
- SR morphine preparations should not be crushed. Therefore patients with nasogastric (NG) or percutaneous endoscopic gastrostomy (PEG) tubes should be given IR morphine preparations. Any patient on SR morphine in whom NG or PEG tube insertion is planned or recently performed needs to be switched to IR morphine tablets.
- Patients with mild-moderate renal impairment should be started ona lower dose, 5mg 6/8hrly. ---Those with moderate to severe impairment should preferably be started on 'renally safe' opioids like TD fentanyl or TD buprenorphine after taking cost into account.

- Patients and caregivers should be educated about morphine, its side effects and their management and the rarity of psychological dependence/addiction.
- For patients with intolerable side effects to morphine change to an alternate strong opioid such as TD Fentanyl or TD Buprenorphine.

PARENTERAL MORPHINE

SC/IV morphine is given when the oral route becomes difficult or unavailable e.g.:

- Dysphagia
- Persistent vomiting
- Bowel obstruction
- Last days or hours of life when swallowing is difficult

IV morphine is 3 times more potent than oral morphine
Calculation of IV morphine dose: 24hr oral dose/3 = 24hr IV dose/6 = 4hrly IV dose
SC morphine is 2-3 times more potent than oral morphine
Therefore SC morphine dose one-third to one-half of oral dose- lower dose should be started so one-third dose give as for IV dose
E.g. A patient on oral morphine 10 mg 4hrly can be started on 3mg SC 4hrly.
Breakthrough dose, equivalent to 50-100% of 4hrly dose may be given every 1-2hr if needed.
Assess the number of breakthrough doses required each day and change the 24hr dose accordingly

EXPERIENCE OF USING ALTERNATE ROUTES OF MORPHINE ADMINISTRATION IN THE HOMECARE SETTING IN INDIA

SC Morphine: If the parenteral route is required the SC route is used. Syringe drivers are usually not used due to the high cost and instead caregivers are taught to give intermittent 4 hrly bolus injections and breakthrough doses as required.

Buccal Morphine: This route is often used in the last hours and days of life. It is often preferred over SC morphine as injection morphine is less easily procured and caregivers maybe unwilling for injections and especially if they have to administer it. Absorption of morphine through this route is slow but it has been found to be effective in most of these patients.

Rectal Morphine: Morphine is absorbed through suppositories. The dose is the same as by the oral route. This route is usually used in moribund patients if oral or SC route is unavailable.

ii. Fentanyl

Fentanyl is a semi synthetic opioid and is a highly selective μ-opioid receptor agonist. It is approximately 80 times as potent as morphine. It is highly lipid soluble (lipophilic) and is extensively taken up into fatty tissue. This lipophilic nature provides an explanation for the difference in side effects as compared to morphine. Fentanyl is transformed into an inactive form, norfentanyl, by the liver and excreted in the urine. Less than 7% is excreted unchanged which is why it is a good option in patients with renal failure.

PREPARATIONS
Patch Strengths: 12.5 mcg, 25mcg, 50mcg, 75mcg, 100mcg.
Onset of action: range- 3-24hr, usually 8-12hrs
Duration of action: 72hrs

Oral Transmucosal Fentanyl Citrate (OTFC) is a taste-masked fentanyl impregnated lozenge on a plastic stick designed for buccal absorption. It is used for breakthrough pain because of it has the advantage of a rapid onset of action (about 5 minutes) and short duration of action (about 2 hours). About half the drug is absorbed directly through the buccal mucosa (which avoids hepatic first pass metabolism), the rest is swallowed and absorbed in the gut. Oral bioavailability is about 50%.
Lozenge strengths: 200 mcg, 400mcg, 600 mcg, 800 mcg, 1200 mcg and 1600 mcg
Onset of action: 5-15min
Duration of action: 2hr
Due to high costs there is very limited of OTFC in our country

SIDE EFFECTS:(see *opioid side effects*)
Side effects of fentanyl are similar to other strong opioids. Some side effects like constipation and nausea and vomiting is less than with morphine

INDICATIONS FOR TD FENTANYL IN PLACE OF MORPHINE:
TD fentanyl is usually not recommended as first-line strong opioid

i. Intolerable side effects with morphine e.g. nausea and vomiting, constipation, hallucinations, etc.

ii. Renal failure
iii. Poor compliance to oral medication
iv. Dysphagia

CONTRAINDICATIONS

i. Acute pain.
ii. Patients requiring rapid titration for severe uncontrolled pain because of the long time to reach effective analgesic concentrations following patch application and the long half-life if overdose occurs. TD Fentanyl should be started in a patient with stable pain.

STARTING TD FENTANYL PATCH

- Careful dose conversion should be done. Two patches may be applied to provide the correct dose.
- The patch should be applied to a dry, non-inflamed, non-irradiated hairless area of skin on the upper trunk or arm. Micropore tape may be used additionally to fix it securely. Body hair may be clipped but not shaved. If the skin is washed before application use only water and do not apply cream or oil.
- The patch should be changed every 3 days (72hr). The application site should also be changed to rest the skin and a particular site may be reused after a week. The date of application or the date of renewal should be written on the patch.
- A person may bathe/shower with the patch on but should not soak in a hot tub.
- Effective systemic analgesic concentrations are usually reached in <12hr. When converting from:

  4hrly IR morphine, continue the 4hrly dose for 12hr after application of patch.
  For 12hrly SR morphine, give the last SR dose at the time of applying the patch
- Steady-state plasma concentrations of fentanyl are achieved within 36-48hr. During the first three days a greater number of rescue doses of IR morphine, given prn, maybe needed.
- If effective analgesia is not achieved throughout the 3 day period, the patch strength should be increased by 12.5-25mcg/hr.
- The appropriate dose of IR morphine should be prescribed for BTP.
- About 10% of patients experience morphine withdrawal symptoms when changed from morphine to a fentanyl patch. Small rescue dose of morphine over a few days will relieve the symptoms.
- Fentanyl causes less constipation than morphine so laxative dose may have to be decreased.

– Nausea and vomiting may occur initially so an anti-emetic like haloperidol 1.5mg should be prescribed stat and at bedtime.

The rate of absorption of fentanyl from the patch may be increased in patients with fever and may result in toxicity e.g. drowsiness and may also occur if a heat pad is applied over the patch. Patients and/or caregivers should be warned about this.

After removal of the patch, significant blood concentrations persist for at least 24hrs so when switching from a patch to another opioid, the latter is started 8-12 hours after removal of patch.

When TD fentanyl dose exceeds 300mcg, additional or alternative analgesics should be used.
In moribund patients continue TD fentanyl. Morphine may be given by SC route if required.
Used patches still contain fentanyl, therefore after removal, fold with the adhesive side facing inwards and discard in sharps container in hospital and in dustbin at home.

APPROXIMATE CONVERSION CHART FROM PO MORPHINE TO TD FENTANYL

PO MORPHINE		TD FENTANYL
mg/24hr	breakthrough dose mg	mcg/hr
30	2.5-5	12
60	5-10	25
90	7.5-15	37.5
120	10-20	50
180	15-30	75
240	20-40	100

III. BUPRENORPHINE

Buprenorphine is a partial mu-opioid receptor and opioid-receptor-like agonist and a k- and δ-opioid receptor antagonist. Buprenorphine does not accumulate in renal impairment and nor is it removed by hemodialysis so analgesia is unaffected. Therefore it may be used in patients with renal failure.

TD Buprenorphine

It is 70-115 times more potent than morphine

Preparations

5mcg, 10mcg, 20mcg- needs to be changed after 7 days

35mcg, 52.5mcg, 70mcg- needs to be changed after 4 days

Indications

i. Intolerable side effects with morphine e.g. nausea and vomiting, constipation, hallucinations, etc
ii. Renal failure
iii. Poor compliance to oral medication
iv. Dysphagia

Patients on TD Fentanyl may be switched to TD Buprenorphine if intolerable side effects e.g. neurotoxicity (hallucinations, myoclonus)

Starting TD Buprenorphine

- Careful conversion from morphine and TD fentanyl needs to be done.
- Appropriate dose of IR morphine should be prescribed for breakthrough pain.
- Buprenorphine causes less constipation than morphine so laxative dose may have to be decreased.
- The patch should be applied to a dry, non-inflamed, non-irradiated hairless area of skin on the upper trunk or arm. Micropore tape may be used additionally to fix it securely. Body hair may be clipped but not shaved. If the skin is washed before application use only water and do not apply cream or oil.
- The patch should be changed after 7 days (5, 10, 20mcg) or after 4 days (35, 52.5, 70mcg). The application site should also be changed to rest the skin and a particular site may be reused after 1-2 weeks. The date of application or the date of renewal should be written on the patch.
- A person may bathe/shower with the patch on but should not soak in a hot tub.
- The rate of absorption of buprenorphine from the patch may be increased in patients with fever and may result in toxicity e.g. drowsiness and may also occur if a heat pad is applied over the patch. Patients and/or caregivers should be warned about this.
- After removal of the patch, significant blood concentrations persist for at least 24hrs so when switching from a patch to another opioid, the latter is started 8-12 hours after removal of patch.
- For BTP tramadol or morphine may be used depending on patch strength.

APPROXIMATE CONVERSION CHART FROM MORPHINE TO TD BUPRENORPHINE

PO MORPHINE			TD BUPRENORPHINE
mg/24hr	breakthrough dose		mcg/hr
12	2.5	5	
24	2.5-5	10	
36	2.5-5	15	
48	5-10	20	
84	7.5-15	35	
126	10-20	52.5	
168	15-30	70	

iv. Tapentadol

Tapentadol is a synthetic centrally acting analgesic which is a mu agonist plus a synaptic re-uptake inhibitor of noradrenaline and is about ≤3 times less potent than morphine i.e. 50 mg tapentadol is equivalent to 15-20mg of morphine

INDICATIONS

Intolerable side effects of morphine
Moderate to severe pain

PREPARATIONS

Tablets IR: 50mg, 75mg, 100mg
Tablets ER (extended release): 50mg, 100mg
Side effects- see opioid side effects
Precautions- Not recommended in patients with liver or renal impairment
Drug interactions
Avoid concurrent use with MAO inhibitors or within two weeks of stopping one
Be alert for serotonin toxicity when used along with SSRIs (anti-depressants)

PRESCRIBING TAPENTADOL

IR tablets- patient should be started on 50mg 4hrly/6hrly if opioid naive and having moderate to severe pain. Higher staring dose can be used in those already on strong opioids.

- If pain relief is inadequate a second dose can be repeated after an hour.
- Dose can be gradually increased to 100mg 4hrly or 150mg 6hrly to a maximum of 600mg/24hrs.

ER tablets- patient should be started on 50mg 12hrly if opioid naïve.
If inadequate pain relief the dose may be increased by 50mg b.d. every 3 days to a maximum dose of 250mg b.d.

v. Methadone

Methadone is a synthetic strong opioid which is a mu receptor agonist, possibly a delta receptor agonist, an NMDA receptor channel blocker and a pre-synaptic blocker of serotonin re-uptake.

INDICATIONS

-Intolerable morphine side effects
-Severe renal impairment
-Severe pain not responding to morphine or other available strong opioids

PREPARATIONS

Tablets- 5mg, 10mg
Suspension- 5mg/ml
Side effects- see opioid side effects

PRECAUTIONS

- Physicians prescribing methadone should be fully aware of its pharmacology.
- Patients who are started on methadone should be closely monitored especially when switching from a high dose of another strong opioid.
- A low dose should be started initially and upward titration should be slow and with close monitoring of patient when dose is changed.
- The patient should be warned not to exceed the prescribed dose.
- Methadone may cause QT interval prolongation and should therefore be used with caution in patients at risk of developing this: history of cardiac conduction abnormalities, family history of sudden death, advanced heart disease or ischemic heart disease, liver disease, electrolyte abnormalities, on drugs which may cause QT prolongation.

PRESCRIBING METHADONE

i. Prescribing methadone as a first-line strong opioid
   a. Methadone should be started at a dose of 2.5mg (1-2mg in elderly) q12h and 2.5mg q3h prn
   b. If required the regular dose may be increased once a week guided by the total prn dose

   c. 2.5mg prn (1-2mg in elderly) dose is continued
   d. When dose is >30mg q12h increase prn dose to 1/6-1/10 of 24hr dose, rounded to a convenient tablet size/volume
2. Prescribing methadone to patients already on morphine
   a. Morphine is stopped abruptly when methadone is started
   b. When switching from IR morphine the first dose of methadone is given ≥2hr (pain present) or 4hr (pain-free) after last morphine dose
   c. When switching from SR morphine the first dose of methadone is given ≥6hr (pain present) or 12hr (pain-free) after the last dose of a 12hr morphine preparation
   d. A single loading dose of methadone is given 1/10 dose of previous 24hr morphine dose upto a maximum of 30mg per dose
   e. For BTP p.r.n. dose is given q3h and is 1/3 of loading dose
   f. If switching from another strong opioid first calculate the morphine equivalent daily dose and then follow the steps given above

SAFETY OF PATIENTS, CAREGIVERS, HEALTH-CARE PROVIDERS, COMMUNITIES AND SOCIETY

Proper and effective stewardship of opioid analgesics is essential to ensure the safety of patients and to reduce the risk of diversion of medicine into society.

Patient assessment should include psychological history, present opioid dosage and any history of substance use, to identify risk factors for improper use and signs of substance use disorders.

To prevent misuse or accidental overdose by children or other family members, family caregivers should be educated on safe storage of opioid analgesics in the home as well as safe disposal or return of unused opioids to homecare team at the end of life or when no longer needed.

REFERENCES

1. Fallon M, Giusti R, Aielli F, Hoskin P, Rolke R, Sharma M, Ripamonti CI, ESMO Guidelines Committee, Management of cancer pain in adult patients: ESMO Clinical Practice Guidelines, Annals of Oncology, 2018; 29 Suppl 4: iv166–iv191
2. Twycross, R., Wilcock, A., Howard, P. Palliative Care Formulary 5+. Nottingham. palliativedrugs.com; 2016. Drug Monogram 5- Analgesics. (pp. 384-581)
3. Fallon M, Cherny NI. Opioid therapy: Optimizing analgesic outcomes. In Hanks G et al (eds). Oxford Textbook of Palliative Medicine 5th ed. Oxford. OUP.pp 524-59
4. 12. Pain-Choosing and changing opioids. www.palliativecareguidelines.scot.nhs.uk (19thAugust 2020).

Analgesics in Pain Management- Adjuvants

An adjuvant analgesic is a drug whose primary action is unrelated to analgesia but acts as an analgesic in some situations e.g. antidepressants, anticonvulsant. Adjuvant analgesics may be added at any step of the WHO ladder.

Adjuvant analgesics used in pain management are:
Antidepressants e.g. amitriptyline
Anticonvulsants e.g. gabapentin, pregabalin
Corticosteroids
Bisphosphonates
Muscle relaxants
Antispasmodics
Topical analgesics

Antidepressants and anticonvulsants
These are used in neuropathic pain

ANTICONVULSANTS- gabapentin, pregabalin

Gabapentin
Starting dose- 300mg hs
Dose increased by 300mg every 2-3 days and given in divided doses e.g.
- 300mg bd
- 300mg tds
- 300mg morning and afternoon and 600mg hs
- 600mg morning, 300mg afternoon, 600mg hs
- 600mg tds

Maximum dose 1800-3600mg/24hrs
Side effects usually limit maximum dose to 1800mg
In elderly and frail patients- starting dose 100mg hs and increased by 100mg/24hrs every 2-3 days
Starting and maximum dose reduced in patients with renal impairment and those on hemodialysis

Pregabalin

Starting dose – 75mg hs; dose increased by 75mg/24hrs every 3-7 days and given in divided doses i.e.
- 75mg bd
- 75mg morning and 150mg hs
- 150mg bd

Maximum dose -600mg/24hrs
In elderly and frail patients- starting dose 25 or 50mg hs and increased by 50mg/24hrs every 2-3 days

Anti-convulsant side effects: Drowsiness, dizziness, ataxia, amnesia, confusion, visual disturbances, dysarthria, tremor, arthralgia, myalgia, peripheral oedema, dry mouth, constipation. Pregabalin may cause QT prolongation.

ANTIDEPRESSANTS– Amitriptyline and nortriptyline. Duloxetine and venlafaxine may be used when former are ineffective.
Precautions: Care should be taken when prescribing other drugs which interfere with serotonin re-uptake e.g tramadol as serotonin toxicity may occur.

Amitriptyline

Starting dose- 10mg hs PO at night and if well tolerated increase to 25mg hs after 3-7 days. If needed may increase by 25mg every 1-2 weeks to a maximum dose of 150mg.

Nortriptyline

Starting dose- 10mg hs PO at night and if well tolerated increase to 25mg hs after 3-7 days. If needed may increase by 25mg every 1-2 weeks to a maximum dose of 150mg.
Side effects: Sedation, postural hypotension, dry mouth, anorexia, vomiting, constipation. When given with tramadol may cause serotonin toxicity.

Second-line drugs in neuropathic pain are the antidepressants venlafaxine and duloxetine.

Venlafaxine

Starting dose: 37.5mg m/r once daily PO and after one week increase to 37.5mg bd.
If needed, increase to 75mg bd after another 2 weeks.
Maximum dose: 225mg

Duloxetine

Staring dose: 30-60mg/day PO in 1-2 divided doses
Maximum dose: 120mg
Side effects: Dizziness, nausea, diarrhoea, dry mouth, constipation, insomnia, restlessness, agitation, drowsiness, headache, sweating, sexual dysfunction

CORTICOSTEROIDS

Corticosteroids have an analgesic effect in many types of cancer pain e.g.

- bone pain
- neuropathic pain from infiltration or compression of nervous tissue
- headache due to increased intracranial pressure from primary or metastatic brain tumors
- liver capsule pain in primary or metastatic liver cancer
- pain due to obstruction of a hollow viscus (e.g. bowel or ureter)

Dexamethasone is the corticosteroid most commonly used because of its low mineralocorticoid effect and its long duration of action which is more than 24hrs
Starting dose: 8-16mg/day PO in 1-2 divided doses.
The initial dose may be given for a 5-7 days and then decreased to 4-8mg.
After 3-4 weeks the dose may be tapered and stopped as there are increased adverse effects on long-term usage.
In some patients the pain may recur when dose is reduced or after withdrawal. In such patients the least effective dose or maintenance dose may be given indefinitely (2-4mg/day). These patients will need regular follow-up and assessment of risks and benefits.
Some patients may not respond to corticosteroids and if there is no pain relief in 5 days the drug may be discontinued without tapering the dose as this is not required if it is given for less than 10 days.

ADVERSE EFFECTS

Corticosteroids have many adverse effects which limit their use. Common adverse effects are:
Infections e.g. candidiasis
Peptic ulceration if given with NSAIDs
Poor control of blood sugar in known diabetics (dose of hypoglycemic drugs to be increased or insulin started)
Diabetes mellitus

Sodium and water retention causing oedema
Osteoporosis
Proximal myopathy
Cataract
Avascular bone necrosis
Cardiomyopathy
Cushingoid features (moon face, buffalo hump, increased abdominal fat)
Acne
Hirsutism

NMDA ANTAGONISTS

Ketamine is a dissociative anaesthetic with a strong analgesic effect in sub-anaesthetic doses.
Indications: It is useful in refractory neuropathic pain. It is also used to prevent pain during procedures.
It may be given PO/SC/IV. It is very potent orally so parenteral route should only be used if oral route is unavailable.
Dose: Oral dose is 0.2-0.5mg/kg given bd or tds in neuropathic pain. This drug should preferably be prescribed by a pain specialist.

Bisphosphonates

Bisphosphonates are analogues of pyrophosphate, a naturally occurring regulator of bone metabolism. They inhibit osteoclast activity and induce their apoptosis.
Indications: They help in reducing metastatic bone pain. As they also help in reducing skeletal-related events (pathological fractures, Spinal cord compression (SCC), hypercalcemia, need for bone radiation or surgery) they are recommended for routine use in metastatic bone pain.
Bisphosphonates: Pamidronate, zoledronic acid, alendronate, ibandronate

Pamidronate

Dose: 90mg IV or SC in 500ml 0.9% saline over 90 minutes repeated every 3-4 weeks

Zoledronic acid

Dose: 4mg IV in 100ml 0.9% saline over 15 minutes, repeated every 3-4 weeks; dose reduced to 3mg in renal impairment

Due to the short infusion duration it is suitable for giving in the homecare setting. It is also more cost effective than ibandronate which has the same infusion duration.

Ibandronate

6mg IV in 100ml 0.9% saline over 15 minutes repeated every 3-4 weeks or 50mg oral od.
The dose is decreased in renal impairment- IV – 4mg, Oral – 50mg alternate days
The oral drug is more convenient but less so than alendronate which can be taken weekly and is also less costly.

Alendronate

70mg oral weekly. Due to the convenient weekly oral dose and comparatively low cost this is suitable for the homecare setting.

Adverse Effects

- Transient fever and flu-like effects with IV bisphosphonates - good response to paracetamol and NSAIDs.
- Fatigue, headache, bone pain, arthralgia, myalgia.
- Renal toxicity - it is reduced by adhering to prescribed dose and infusion rate, ensuring good hydration, monitoring renal function and discontinuing the drug if impairment occurs.
- Osteonecrosis of jaw – usually occurs 1-3yrs after starting the drug. For prevention advise good dental hygiene, avoiding dental procedures during treatment and minimizing trauma to jaw e.g. using soft liners for dentures.
- Insomnia.
- Oral drugs may cause GI symptoms like dyspepsia, nausea, vomiting, abdominal pain, diarrhoea or constipation. To minimize these effects oral drugs should be taken empty stomach in the morning and food taken after 30 minutes. Patient should also preferably remain upright for one hour after taking the drug.

SKELETAL MUSCLE RELAXANTS

Muscle relaxants are used to relieve pain due to chronic muscle spasm or spasticity resulting from neural injury.
Muscle relaxants used are- Baclofen, tinazidine, diazepam

Baclofen

Contraindicated: In active peptic ulcer disease as it increases gastric acid secretions
Starting dose: 5mg bd to tds PO; maximum dose – 20mg qid

Side effects: Weakness, sedation, dizziness, nausea
Precations: Avoid abrupt withdrawal as it may cause agitation, psychoses and seizures

Tizanidine

Starting dose: 2-4mg hs PO; maximum dose – 12mg tds
Side effects: Drowsiness, weakness, dry mouth, hypotension, nausea
Precautions: Use with caution with antihypertensives or digoxin
Avoid abrupt withdrawal as it may cause rebound hypertension and tachycardia

Diazepam

Starting dose: 2-5mg hs PO; maximum dose – 60mg/24hrs
Side effects: Weakness, sedation, cognitive impairment
Precautions: Avoid abrupt withdrawal as it may cause rebound anxiety and insomnia

SMOOTH MUSCLE RELAXANTS

Antispasmodics are used for smooth muscle spasm like in bowel colic – hyoscine butylbromide

Hyoscine butylbromide

Hyoscine butylbromide is poorly absorbed when taken orally but as it has a high affinity for muscarinic receptors it remains available at the site of action in the intestine and exerts a local antispasmodic effect
Dose: 10-20mg tds to qid PO
20mg SC
Side effects: Tachyarrhythmias (more in elderly), hypotension,headache, dizziness, dry mouth, nausea, constipation, increased intra-ocular pressure, drowsiness, confusional states, hallucinations, blurred vision, eye pain,

TOPICAL ANALGESICS

Topical analgesics are applied directly at the site of pain and may provide relief with minimal side effects.

Commonly available topical analgesics are NSAIDS and local anaesthetics in cream and gel form e.g. diclofenac gel, xylocaine cream and gel and xylocaine viscous as an oral rinse.

ADJUVANT ANALGESICS IN PAIN MANAGEMENT

DRUG	USUAL DOSE	COMMENTS
Anticonvulsants		
Gabapentiin Pregabalin	Starting dose: 300mg hs Increase by 300mg every 2-3 days Maximum dose: 1800-3600mg Starting dose: 75mg hs Increase by 75mg every 3-7 days Maximum dose: 300mg	These are first line drugs for neuropathic paingiven alone or in combination with antideprssants Side effects usually limit maximum dose of gabapentin to 1800mg Lower starting dose in elderly
Antidepressants		
Amitriptyline, Nortriptyline Venlafaxine Duloxetine	Starting dose: 10mg hs If well tolerated increase to 25mg after 3-7days Increase by 25mg every 1-2 weeks Maximum dose: 150mg Starting dose: 37.5mg m/r once daily PO; increase to 37.5mg bd after 1 week If needed, increase to 75mg bd after another 2 weeks Staring dose: 30-60mg/day PO in 1-2 divided doses	Amitriptyline and nortriptyline are first line drugs for neuropathic pain and may be given alone or in combination with gabapentin or pregabalin Duloxetine & venlafaxine are second line drugs in neuropathic pain
Corticosteroids		
Dexamethasone	Starting dose: 8-16mg PO x 5-7 days Then decrease to 4-8mg x 2-3 weeks & taper off If pain recurs least effective dose (2-4mg) continued indefinitely	Dexamethasone is preferred steroid because of low mineralocorticoid effect and long duration of action (>24hr) If no relief in pain in 3-5 days discontinue drug
Bisphosphonates		
Zoledronic acid Ibandronate	4mg IV in 100ml NS over 15 minutes 6mg IV in 100ml NS over 15 minutes	Dose of bisphosphonates is reduced in renal failure For prevention of osteonecrosis of jaw-good dental hygiene, avoid dental procedures during treatment, minimize trauma to jaw

Alendronate	70mg PO once a week	
Skeletal Muscle Relaxants		
Baclofen	Starting dose:5mg PObd or tds Maximum dose – 20mg qid	Contraindicated in active peptic ulcer
Tinazidine	Starting dose:2-4mg PO hs Maximum dose – 12mg tds	Avoid abrupt withdrawal as it may cause rebound hypertension and tachycardia
Diazepam	Starting dose: 2-5mg PO hs Maximum dose – 60mg/24hrs	Avoid abrupt withdrawal as it may cause rebound anxiety and insomnia
Smooth Muscle Relaxants		
Hyoscine butylbromide	Dose: Oral- 10-20 tds SC- 20mg sos	Poorly absorbed orally but exerts a local antispasmodic effect in intestines

REFERENCES

1. Twycross, R., Wilcock, A., Howard, P. Palliative Care Formulary 5+. Nottingham.. palliativedrugs.com; 2016.
2. Lussier D, Portenoy RK. Adjuvant analgesics. In Hanks G et al (eds). Oxford Textbook of Palliative Medicine 5th ed. Oxford. OUP.pp 577-588
3. Lussier D, Huskey AG, Portenoy RK. Adjuvant analgesics in cancer pain management. Oncologist. 2004; 9:571-591
4. Watson M, Armstrong P, Gannon C, Sykes N, Back I (eds). Palliative Adult Network Guidelines 4th ed.; 2016
5. Twycross R, Wilcock A(eds). Introducing Palliative Care. Khozikode, palliativedrugs.com; 2016
6. Tytgat GN. Hyoscine butylbromide: a review of its use in the treatment of abdominal cramping and pain. Drugs. 2007;67(9):1343-57

Difficult Pain Management

A. NEUROPATHIC PAIN

Neuropathic pain occurs as a result of a lesion or disease of the peripheral or central somatosensory nervous system. Examples of peripheral neuropathy are diabetic peripheral neuropathy, chemotherapy-induced peripheral neuropathy, phantom limb pain, radicular pain (RP), and postsurgical chronic neuropathic pain (PSCP). Examples of central neuropathy include multiple sclerosis, post-stroke pain, spinal cord injury-related pain, post-herpetic neuralgia (PHN), complex regional pain syndrome (CRPS), and trigeminal neuralgia (TN).

In cancer patients neuropathic pain occurs to due to nerve damage caused by a primary cancer or metastases or due to cancer treatment i.e. surgery, chemotherapy or radiotherapy. Neuropathic pain is often difficult to treat and significantly impacts the patient's quality of life.

Assessment (refer to *pain assessment guideline*)

- History of disease or lesion affecting the nervous system.
- A complaint of pain in a dermatomal or neuro-anatomical area compatible with disease/lesion.
- The quality of pain may be described as burning, pins and needles (paraesthesia), tingling, numbness, electric current-like, shooting, crawling, and intolerance to temperature. Some patients may complain of pain from stimuli that are not usually painful (allodynia) or excessive pain from normally painful stimuli (hyperalgesia).

Management of neuropathic pain

- Neuropathic pain should first be managed according to WHO guidelines using non-opioids and/or opioids and about half the patients will respond to this. The remainder can be managed with the addition of adjuvant analgesics or non-pharmacological measures e.g. TENS, nerve block.
- An adjuvant analgesic is a drug whose primary action is not related to analgesia e.g. antidepressants, anticonvulsant.
- Adjuvant drugs commonly used for neuropathic pain are anticonvulsants and antidepressants. Drugs from both groups may be prescribed together.
- These drugs are started at a low dose and titrated upwards till adequate analgesia is obtained or unacceptable side effects occur. In elderly and frail patients a lower dose should be started.

Anticonvulsants - gabapentin and pregabalin
Anti-depressants- amitriptyline and nortriptyline

Anticonvulsants- gabapentin, pregabalin

GABAPENTIN-
Starting dose- 300mg hs
Dose increased by 300mg/24hrs every 2-3 days and given in divided doses i.e.
- 300mg bd
- 300mg tds
- 300mg morning and afternoon and 600mg hs
- 600mg morning, 300mg afternoon, 600mg hs
- 600mg tds

Maximum dose 1800-3600mg/24hrs
Side effects usually limit maximum dose to 1800mg
In elderly and frail patients- starting dose 100mg hs and increased by 100mg/24hrs every 2-3 days
Starting and maximum dose reduced in patients with renal impairment and those on hemodialysis

PREGABALIN-
Starting dose - 75mg hs; dose increased by 75mg/24hrs every 3-7 days and given in divided doses i.e.
- 75mg bd
- 75mg morning and 150mg hs
- 150mg bd

Maximum dose -600mg/24hrs
In elderly and frail patients- starting dose 25 or 50mg hs and increased by 50mg/24hrs every 2-3 days

Anti-convulsant side effects: Drowsiness, dizziness, ataxia, amnesia, confusion, visual disturbances, dysarthria, tremor, arthralgia, myalgia, peripheral oedema, dry mouth, constipation. Pregabalin may cause QT prolongation.

Antidepressants- Amitriptyline and nortriptyline; duoloxetine and venalfaxine may be used when former are ineffective.

AMITRIPTYLINE
Starting dose- 10mg hs at night and if well tolerated increase to 25mg hs after 3-7 days.
If needed may increase by 25mg every 1-2 weeks to a maximum dose of 150mg.

NORTRIPTYLINE:
Starting dose- 10mg hs at night and if well tolerated increase to 25mg hs after 3-7 days.
If needed may increase by 25mg every 1-2 weeks to a maximum dose of 150mg.
Side effects: Sedation, postural hypotension, dry mouth, anorexia, vomiting, constipation. Nortriptyline is less sedating than amytriptyline.

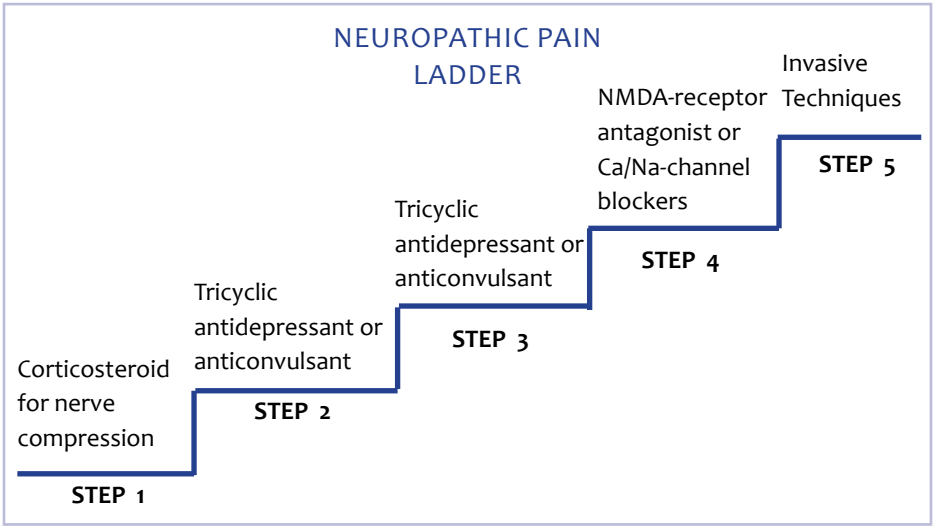
Second-line drugs in neuropathic pain are the antidepressants duoloxetine, venlafaxine
VENLAFAXINE
Starting dose: 37.5mg m/r once daily PO and after one week increase to 37.5mg bd.
If needed, increase to 75mg bd after another 2 weeks
Maximum dose: 225mg/24hrs

DULOXETINE
Staring dose: 30-60mg/day PO in 1-2 divided doses
Maximum dose: 120mg/24hrs
Side effects: Dizziness, nausea, diarrhoea, dry mouth, constipation, insomnia, restlessness, agitation, drowsiness, headache, sweating, sexual dysfunction

CORTICOSTEROIDS may also be used in neuropathic pain when there is nerve compression e.g. in SCC (for SCC see guideline) or it may be added when there is incomplete response to antidepressants and antiepileptics.

Dexamethasone is the preferred steroid due to low mineralocorticoid effect and long duration of action.
Starting dose – 8-16mg/day PO in 1-2 divided doses.
The initial dose may be given for a 5-7 days and then decreased to 4-8mg.
After 3-4 weeks the dose may be tapered and stopped as there are increased adverse effects on long-term usage.
In some patients the pain may recur when dose is reduced or after withdrawal. In such patients the least effective dose or maintenance dose may be given indefinitely (2-4mg/day). If no relief in pain discontinue the steroid after 3-5 days.

NMDA Antagonist like ketamine may be used in refractory neuropathic pain. Oral dose is 0.2-0.5mg/kg given bd or tds. This should preferably be prescribed by a pain specialist.



The neuropathic pain ladder may be used to guide management of neuropathic pain.
Step 1: If nerve compression is suspected/diagnosed as in SCC, a corticosteroid may be started i.e. dexamethasone 8-16mg od for 5-7 days and then decreased to minimum effective dose.
Step 2: Where neuropathic pain is not responsive to non-opioids and/or opioids the patient may be started on a tricyclic antidepressant e.g. amitriptyline or anticonvulsant e.g. gabapentin
Step 3: If there is inadequate pain relief with step 2 drugs then a combination of a tricyclic antidepressant and anticonvulsant may be given
Step 4: If inadequate pain relief with step 3 drugs then NMDA-receptor antagonist e.g. ketamine, may be started
Step 5: The patient may be referred to hospital for invasive or interventional techniques if oral drugs are ineffective.

b. Strategies for Management of Mixed Cancer Pain

Cancer pain occurs due to nociceptive or neuropathic damage or both which is a result of the disease or its treatment i.e. radiotherapy, chemotherapy or surgery.

Following the WHO analgesic ladder allows for pain relief in 70-90% cancer patients
Strategies for managing pain in specific painful situations:

- Neuropathic pain- antidepressants or anticonvulsants can be added to drugs already prescribed. Corticosteroids may also be prescribed (see guideline on neuropathic pain).
- Headache due to increased intracranial pressure due to primary brain tumor or brain metastases may be managed by adding corticosteroids like dexamethasone started at a dose of 8mg od x 7-10 days and then gradually reduced to least effective dose after 7-10 days.
- Right hypochondriac pain due to stretching of liver capsule in patients with primary or metastatic liver cancer may be managed by adding corticosteroids- dexamethasone 8mg od x 7-10 days weeks and gradually reduced to least effective dose.
- Bowel colic does not usually respond to morphine but may be relieved by antispasmodics such as hyoscine butylbromide.

Experience in pain management in a homecare setting in India

- 70-90% cancer patients' pain can be managed by following the WHO analgesic ladder.
- NSAIDs are often needed to relieve pain in head and neck cancer patients.
- In patients with malignant wounds with bleeding and who require NSAIDs, COX-2 inhibitors like etoricoxib can be prescribed.
- Morphine is effective in relieving severe cancer pain in the majority of patients.
- Alternative strong opioids like TD fentanyl or TD buprenorphine maybe prescribed when there are persistent or intolerable side effects like vomiting, severe constipation, presence of nightmares or urinary retention, in malignant bowel obstruction or patient has too many medications. However the cost of patches is high is often not a viable alternative in the lower socio-economic group.
- Neuropathic pain is usually relieved with anticonvulsants or antidepressants and steroids may be added if incomplete relief with the former.
- In the last days and hours of life if swallowing becomes difficult morphine given sublingually provides effective pain relief in most patients.

REFERENCES

1. Fallon M, Giusti R, Aielli F, Hoskin P, Rolke R, Sharma M, Ripamonti CI, ESMO Guidelines Committee, Management of cancer pain in adult patients: ESMO Clinical Practice Guidelines, Annals of Oncology, 2018; 29 Suppl 4: iv166–iv191.
2. Finnerup NB, Jensen TS. Management issues in neuropathic pain. In Hanks G et al (eds). Textbook of Palliative Medicine; 5th ed. Oxford. OUP. p 860-66
3. Colvin L, Forbes K, Fallon M. In Fallon M, Hanks G (eds) ABC of Palliative Care 2nd ed. Oxford. Blackwell Publishing. pp. 8-12
4. Twycross, R., Wilcock, A., Howard, P. Palliative Care Formulary 5+. Nottingham.. palliativedrugs.com; 2016. Drug Monogram 4-Central nervous system . (pp. 207-383)
5. Twycross, R., Wilcock, A., Howard, P. Palliative Care Formulary 5+. Nottingham. palliativedrugs.com; 2016. Drug Monogram 7- Endocrine system and immunomodulation (pp 615- 682)
6. Chung C. Pharmacologic management of cancer-related pain. US Pharm. 2021;46(3):HS1-HS10
7. Lussier D, Huskey AG, Portenoy RK. Adjuvant analgesics in cancer pain management. Oncologist. 2004; 9:571-591

Respiratory Symptoms

A. DYSPNOEA OR BREATHLESSNESS

Definition: The American Thoracic Society defines dyspnoea as "a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity. It can be associated with any combination of physiological, psychological, social and spiritual factors. Dyspnoea and breathlessness can be used interchangeably.

Breathlessness is a common symptom for patients with advanced cancer, chronic obstructive pulmonary disease (COPD), pulmonary fibrosis and heart failure. The impact and distress caused by it is often underestimated.

Prevalence in Cancer Patients- about 50% of the general cancer population

TABLE 8: CAUSES OF BREATHLESSNESS IN CANCER PATIENTS

CANCER RELATED	TREATMENT RELATED	OTHER CAUSES
Airway obstruction +/- lung collapse Superior vena cava obstruction Lymphangitiscarcinomatosis Tumour emboli Lung infiltration Respiratory muscle weakness Pleural effusion Phrenic nerve palsy Splinting of the diaphragm; ascites, hepatomegaly Chest wall infiltration Anaemia Tumour en cuirasse Chest wall pain	Surgery; lobectomy, pneumonectomy Radiation pneumonitis Chemotherapy; methotrexate, cyclophosphamide Drugs precipitating fluid retention or bronchospasm, eg corticosteroids, beta-blockers	Psychological factors e.g. fear, anxiety, anger, depression Infection Pre-existing chronic respiratory disease Pre-existing chronic cardiac disease Pulmonary oedema Pneumothorax Pulmonary embolism

Assessment

Undertake a holistic assessment
Ask the patient to rate symptom severity and assess the level of associated distress/ anxiety.
Explore the patient's understanding of the reasons for breathlessness, fears, impact on functional abilities and quality of life.
Clarify pattern of breathlessness, precipitating/alleviating factors and associated symptoms.
Look for any potentially reversible causes of breathlessness, such as infection, pleural effusion, anemia, or hypoxia (check oxygen saturation levels using pulse oximeter if available).
Determine if treatment of the underlying disease is appropriate. Seek advice if in doubt.
If in last days of life, manage according to 'Last Days of Life' guideline.

Management:

Determine and treat any potentially reversible causes if appropriate.
Optimise current therapy (non-pharmacological and pharmacological management).
Acknowledge fear and anxieties and provide supportive care. For example, offer verbal explanation of symptom and written information.

Potentially Reversible Causes:

Lung cancer- Chemotherapy in selected patients; targeted therapy in adenocarcinoma lung with epidermal growth factor receptor mutation
Superior vena cava obstruction (SVCO)-Stenting, radiotherapy, chemotherapy, corticosteroids, diuretics
Pleural effusion- Thoracocentesis, pleurodesis
Lymphangitiscarcinomatosis- Steroids
Respiratory infection- Antibiotics
COPD/Asthma- Bronchodilators and corticosteroids
Ascites- Abdominal paracentesis, diuretics
Anaemia- Blood transfusion

Non-pharmacological Management:

Allow patients to assume position of comfort (propped up, sitting, semi-sitting)
Use hand-held fan or open window to improve ventilation.

Relaxation and anxiety management techniques
Breathing techniques- pursed lip breathing
Pacing of activities

Pharmacological management

A) OPIOIDS

Opioids act on the CO_2-sensitive medullary respiratory centre, but may also act on other sites to reduce the sensation of breathlessness.
Can reduce breathlessness at rest and in the end-of-life phase.
Give as a therapeutic trial; monitor patient response and side effects.
Consider proactive prescribing for constipation and nausea and vomiting.

For opioid naïve patients, morphine PO 2.5-5mg PO prn
If effective, use morphine PO regularly, initially 12hrly or 8hrly increasing to 6hrly or 4hrly if breathlessness increases
For patients already on regular opioids for pain relief increase dose by 50-100% of 4hrly dose.
In patients who are unable to swallow, morphine may be given subcutaneously as prn or regular bolus doses
In elderly patients, especially those >75yrs, doses as low as 1-2mg q12h

B) BENZODIAZEPINES

May relieve anxiety and panic associated with severe breathlessness, but are less effective than opioids for breathlessness and should be a third-line treatment for patients with symptoms unresponsive to non-drug measures and opioids. The following can be considered:
Lorazepam 0.5- 2mg SL given 4 to 6 hourly as required
Diazepam oral 2mg to 5mg at night, if there is continuous distressing anxiety.
Midazolam SC 2mg to 5mg, given 4 to 6 hourly as required, if oral or sublingual routes are not available.
Lorazepam has an advantage over diazepam during breathlessness panic attacks as it can be given sublingually, has a quick onset and is short acting.

C) STEROIDS

i. Trial of dexamethasone 8-16mg given in SVCO, major airway obstruction, lymphangitis carcinomatosis, radiation pneumonitis

ii. Review treatment after 5 days and if effective gradually decrease to lowest therapeutic dose
iii. If ineffective discontinue treatment

D) OXYGEN

Oxygen has been shown to be superior to placebo in symptomatic, hypoxic, advanced cancer patients but it also has a placebo effect in some patients and gives immense satisfaction to the caregiver. It should be started after careful individual patient assessment.

If oxygen saturation is less than 92%, consider a trial of oxygen for symptom relief. Be aware that there may be a poor relationship between hypoxaemia and breathlessness and response to oxygen.

E) BRONCHODILATORS

Indicated in COPD, lung cancer with COPD or asthma or those with wheeze- salbutamol + ipratropium bromide nebulized/inhaler tds/qid

F) NEBULIZED NORMAL SALINE- MAY HELP IN EXPECTORATION

Experience of managing breathlessness in a homecare setting in India
Breathlessness is difficult to manage especially in the terminal phase and is one of the main reasons for emergency hospital visits at this time and may result in hospital death.

Morphine is the drug of choice for managing breathlessness at this time and maybe given orally or subcutaneously. It should be prescribed as an anticipatory medication especially in those with a primary lung cancer or lung metastases.

If the patient is already on morphine for pain the dose can be increased by 50-100%. If the patient is opioid-naïve then 2.5-5mg tds or q6h may be given.

REFERENCES

1. Symptom control-breathlessness.www.palliativecareguidelines.scot.nhs.uk (16th August 2020)
2. Chan KS, Tse DMW, Sham MMK. Dyspnoea and other respiratory symptoms in palliative care. In: Hanks G et al (eds). Textbook of Palliative Medicine. 5th ed. Oxford: OUP; 2015. p. 801-12

B. COUGH

Cough is a normal but complex physiological mechanism that protects airways and lungs by removing mucus and foreign matter from larynx, trachea, and bronchi, and is under both voluntary and involuntary control.

Cough is a common symptom in cancer especially lung cancer and COPD patients. It may cause chest pain, urinary incontinence, sweating, exhaustion, and disturbance of sleep and thus adversely affect patient's quality of life.

Causes:

Due to cancer
Lung cancer (primary or metastases)
Lymphangitiscarcinomatosis
Intrinsic or extrinsic airway obstruction by tumour
Pleural effusion
Pleural tumour (primary or implant)
Multiple tumormicro-emboli
Superior vena cava syndrome

Due to Treatment
Radiotherapy sequelae
Chemotherapy induced (eg, bleomycin, cyclophosphamide)
Chemotherapy-induced cardiomyopathy (eg, adriamycin)

Due to Debility
Anorexia-cachexia syndrome
Pulmonary aspiration
Pulmonary embolus

Unrelated to Cancer
Asthma
Gastroesophageal reflux disease
Chronic bronchitis
Bronchiectasis
Angiotensin-converting enzyme (ACE) inhibitor drugs
Noncancerous Diseases- Neuromuscular Pathology

Multiple sclerosis
Amyotrophic lateral sclerosis
Hereditary ataxia
Late-stage dementia (irrespective of type)
Cerebrovascular disease

Assessment

History and physical examination
Ask about when cough started, severity, nocturnal or diurnal, productive or non-productive, any associated distress and anxiety
Determine:
Any aggravating or relieving factors
Effect of cough on sleep, continence, quality of life, family and caregivers
Any associated symptoms
Look for potentially reversible causes of cough like infection, pleural effusion, pulmonary embolism, bronchospasm, ACE inhibitors
Investigations: Chest X-ray,

Management

a) Treatment of potentially reversible causes- cancer related or non-cancer related
Cancer-related e.g. steroids to reduce tumor oedema, airway obstruction, lymphangitiscarcinomatosis, antibiotics for chest infection, thoracocentesis for pleural effusion.
Non-cancer related e.g. discontinuation of ACE Inhibitors, bronchodilators in asthma, proton pump inhibitors for gatro-oesophageal reflux disease.

b) Non-pharmacological
General measures
Positioning/posture
Opening a window or using a fan
Discontinuing cigarettes/bidis
Breathing techniques and effective coughing techniques e.g. huffing
For thick secretions
Steam inhalation
Nebulised saline
Chest Physiotherapy

c) Pharmacological

1) Anti-tussives

Used to suppress cough in symptomatic treatment of dry cough

Anti-tussives may be divided into centrally acting and peripherally acting

Centrally acting ant-tussives are usually opioids that suppress cough through the μ-opioid receptors in the central nervous system and peripherally acting antitussives act on the sensory afferents.

Commonly used centrally acting anti-tussives are:

i. Morphine: In opioid-naïve- 2.5mg 4-6 hrly or 6-8 hrly if elderly/frail or in renal or hepatic impairment

    In those on regular morphine increase 4 hrly dose by 25%

ii. Codiene- a pro-drug which is metabolized by the liver into morphine, norcodiene, hydromorphine and hydrocodone.

    Dose - 10-20mg every 4 hrs as needed

iii. Dextromethorphan- a non-opioid which is more effective and has fewer side effects than codiene.

    Dose – 10-20mg 4-8 hrly

Peripherally acting anti-tussives:

i. Sodium cromoglycate inhaler: 2 puffs twice daily (40mcg/day)
ii. Benzonatate- 100-200 mg tid (patient advised not chew the capsule to prevent local anaesthetic effects in oropharynx)
iii. Gabapentin- for refractory chronic cough- 100-300mg 8 hrly

2) Mucolytics/expectorants

For productive cough- facilitate expectoration by reducing viscosity of purulent and non-purulent pulmonary secretions

i. N-acetylcystiene – commonlyused as mucolytic in COPD- 600mg od (effervescent tablet)
ii. Ambroxol– available as tablet and syrup- dose - 30mg tds
iii. Guaiphenasin and bromhexine- available in syrups in combination with bronchodilators

REFERENCES

1. Bonneau A. Cough in the palliative care setting. Can Fam Physician. 2009;55(6):600-602.
2. Symptom control-Cough.www.palliativecareguidelines.scot.nhs.uk (16th August 2020
3. Chan KS, Tse DMW, Sham MMK. Dyspnoea and other respiratory symptoms in palliative care. In Hanks G et al (eds). Textbook of Palliative Medicine 5th ed.Oxford.OUP.p 801-12

Management of Gastrointestinal Symptoms

A. NAUSEA AND VOMITING

Nausea& vomiting are common symptoms in advanced diseases and management may be difficult as a number of factors may be involved.

Definitions

Nausea is an unpleasant subjective sensation with a feeling of the need to vomit
Vomiting is the forceful expulsion of gastric contents through the mouth by sustained contraction of abdominal musculature and diaphragm.

Common causes of nausea and vomiting

CHEMICAL

- Drugs (opioids, cytotoxics, antibiotics)
- Metabolic (organ failure, hypercalcaemia, hyponatraemia)

GASTROINTESTINAL STRETCH OR IRRITATION

- Drugs (NSAIDs, iron supplements, antibiotics, steroids, cytotoxics)
- Constipation
- Intestinal obstruction
- Liver metastases
- Retroperitoneal cancer

GASTRIC STASIS

- Drugs (anticholinergics, opioids, tricyclics)
- Ascites
- Hepatomegaly
- Peptic ulcer
- Gastritis (caused by stress, drugs or radiotherapy)
- Autonomic failure

RAISED INTRACRANIAL PRESSURE

- Bleeding
- Cerebraloedema
- Meningealtumour
- Skull metastases

MOVEMENT-RELATED
- Opioids
- Gut distortion
- Gastroparesis

ANXIETY-RELATED
- Anxiety
- Anticipatory vomiting (for example pre-chemotherapy)

Assessment

History- separate history for both nausea and vomiting

i. Nausea
   When did it start, duration, intensity?
   What makes it better or worse?
   Is it accompanied by vomiting?
ii. Vomiting
   Volume, colour, force, timing i.e. any relation to meals or time of day
   Preceded by nausea
iii. Other symptoms
   Any associated symptoms e.g. dyspepsia, heartburn, early satiety, constipation, diarrhoea, flatus, headache, confusion
iv. Treatment history
   All medications used to treat nausea and/or vomiting and efficacy
   Is the patient on chemotherapy or radiotherapy?
   All medications patient is taking and any recent additions related to start of symptoms

Examination

i. Check BP, pulse, temperature, respiration and look for of signs of dehydration or infection.
ii. Exam oral cavity for thrush.
iii. Abdominal examination- distension, ascites, hepatomegaly, masses, bowel sounds.
iv. Rectal examination- If h/o constipation ≥5 days or h/o prolonged constipation followed by(overflow Diarrhoea).

Investigations (only if required):

i. Kidney function tests (includes serum calcium)
ii. Serum electrolytes
iii. Liver function tests
iv. Abdominal X-ray (erect) if possible - for suspected malignant bowel obstruction

Management of Nausea and Vomiting

1. NON-PHARMACOLOGICAL MANAGEMENT

- Avoidance of cooking smells
- Presentation of small attractive meals
- Cool fizzy drinks- more palatable than hot, still drinks
- Attention to unpleasant odours e.g. from fungating wound

2. TREAT REVERSIBLE CAUSES:

- Drug-related- stop drug
- Constipation- prescribe laxative
- Hypercalcemia- bisphosphonates

3. PHARMACOLOGICAL MANAGEMENT

The mechanistic approach to the management of nausea and vomiting

i. Identify the likely cause(s) of nausea and/or vomiting.
ii. Identify the pathway by which each cause triggers the vomiting reflex.
iii. Identify the neurotransmitter receptor involved in the identified pathway.
iv. Choose the most potent antagonist to the receptor identified.
v. Choose a route of administration that ensures that the drug reaches its site of action—this often excludes the oral route.
vi. Titrate the dose carefully, review the patient frequently.
vii. Give the antiemetic regularly.
viii. If symptoms persist, review the likely cause(s): additional treatment may be required for an overlooked cause, or alternative treatment may be suggested by a different cause becoming apparent.
ix. If combining anti-emetics, potential drug interactions need to be considered. For example, an antihistamine or anticholinergic may counteract the effects of a prokinetic agent.

CHOICE OF ANTI-EMETIC ACCORDING TO CAUSE AND RECEPTORS INVOLVED:

CAUSE	DRUG OF CHOICE& DOSE	RECEPTOR & SITE	REMARKS
Gastric Stasis Ileus	Metoclopramide 10mg tds PO/SC Maximum dose – 120mg/day	D2CTZ D2 GIT-Prokinetic	Prokinetic
Opioid-induced	Haloperidol 1.5mg bd PO/SC Maximum dose – 5mg/day Metoclopramide 10mg tds PO/SC	D2 CTZ D2 CTZ	Haloperidol is the drug of choice
Chemotherapy	Ondansetron 4-8mg tds PO/IV/SC Granisetron 1-2mg bd PO/IV Apprepitant 125mg one hour before chemotherapy, then 80mg od x 2 days	5HT3 CTZ NK1 Widespread	Given in combination with dexamethasone Only available as tablet
Metabolic Disorder	Haloperidol 1.5mg bd PO	D2	
Malignant Bowel Obstruction	Hyoscine butylbromide 20-40mg q8h SC Maximum dose 240mg/day	Ach GIT	Does not cross BBB so non-sedative Poorly absorbed from GIT
Raised ICP	Dexamethasone 8mg od PO	Reduction in cerebral oedema	
Anticipatory Nausea	Benzodiazepines: Diazepam 5mg hs PO Lorazepam 0.5-1mg hs PO	GABA Higher 5HT cortical centres	
Vertigo	Cinnarizine 25mg tds PO Betahistine 8-16mg bd PO	H1 Vestibular apparatus	

Special Points

1. If patient does not respond to oral medication, give drugs SC
2. Prescribe drug regularly and as required
3. Don't combine prokinetic with anti-cholinergic or anti-histaminic
4. Review treatment and response every 24hrs till symptoms are controlled
5. 1-2 episodes of vomiting allowed in intestinal obstruction
6. Good mouth care essential

REFERENCES

1. Kelly B, Ward K. Nausea and vomiting in palliative care. Nursing Times.2013; 109: 39, 16-19.
2. Symptom control -Nausea/Vomiting www.palliativecareguidelines.scot.nhs.uk (19thAugust 2020).
3. Stephenson, J. and Davies, A. An assessment of aetiology-based guidelines for the management of nausea and vomiting in patients with advanced cancer. Supportive Care in Cancer. 2006; 14, 348–353.
4. Hardy JR, Glare P, Yates P, Mannix KA. Palliation of nausea and vomiting. In Hanks G et al (eds).Textbook of Palliative Medicine 5th ed. Oxford. OUP.p 801-12

B. CONSTIPATION

Constipation is the passage of small, hard faeces infrequently and with difficulty and with the frequency being less often than is normal for that person. Due to constipation a person may complain of other symptoms like bloating, nausea and vomiting, abdominal and rectal pain and a feeling of incomplete evacuation.

Even in the absence of oral intake small quantities of stool are produced daily. Many palliative care patients have decreased intake and therefore decreased frequency of bowel movement. As long as the stool is soft and easy to pass frequency of once in 2-3 days is acceptable.

Causes of Constipation

I. CANCER-RELATED

Malignant bowel obstruction
Spinal cord compression
Hypercalcemia
Vomiting
Poor intake

II. TREATMENT-RELATED

Drugs- opioids, 5-HT3 antagonists, anti-cholinergics

III. ASSOCIATED FACTORS/CONCURRENT ILLNESS
Decreased mobility
Weakness
Difficulty accessing toilet facilities
Terminal phase
Uraemia, hypokalemia
Hypothyroidism
Depression

Assessment

- Bowel history
- Patient's normal bowel habit
- Current stool characteristics- volume, consistency, colour, blood
- Review of laxatives taken, current and past and their effectiveness
- Other symptoms: abdominal pain, nausea, vomiting, flatulence, sense of incomplete evacuation, overflow Diarrhoea, urinary retention
- Abdominal and per rectal examination
- X-ray abdomen erect to rule out intestinal obstruction

Management

The aim of management is comfortable defecation and not a particular frequency of bowel motion
Treat the reversible causes
Non-pharmacological management
Pharmacological management

Non-Pharmacological Management

These measures should also be used to prevent constipation

- Privacy and comfort and easy access toilet facilities e.g. commode, hand rails in toilet, raised toilet seat
- Increased fluid and fibre intake to extent possible
- Increased activity if feasible

Pharmacological Management

In patients presenting with Diarrhoea there is a need to differentiate between true Diarrhoea and overflow Diarrhoea caused by fecal impaction.

Avoid mixing two laxatives of the same type e.g. two stimulants.
Avoid using bulk laxatives in palliative care patients.

Laxative regimes should be individually tailored for the patient and each laxative should be titrated according to the effect and patient tolerance .

All patients started on strong opioids should be prescribed laxatives.

Constipation may be the cause of agitation in a dying patient. Relieving the constipation with suppositories or enema will give complete relief from agitation.

First line treatment:

A) STIMULANT LAXATIVE OR SOFTENER
Tab Bisacodyl 10mg hs
Tab Sodium picosulphate 10mg hs
Syp Cremaffin (Magnesium hydroxide and Liquid Paraffin) 10-20ml hs
Syp Lactulose 10-20ml hs

B) STIMULANT AND SOFTENER
Tab Bisacodyl 10mg hs and Syp Cremaffin 10-20ml hs or bd
Tab Sodium picosulphate 10mg hs and Syp Cremaffin 10-20ml hs or bd
Syp Cremaffin plus (Magnesium hydroxide, Liquid Paraffin and Sodium picosulphate) 10-20ml hs or bd
Tab Sodium picosulphate 10 mg hs plus Syp Lactulose 10-20ml hs or bd

C) MACROGOLS
Polyethylene glycol (laxopeg) 1-2 sachets/day

Second line treatment

Rectal suppositories and enema
Bisacodyl suppositories- if no response to oral laxatives
Per rectal examination to be done if no bowel movement >4days or rectal discomfort
Soft stool-Bisacodyl suppositories or sodium phosphate enema

Third line treatment

Manual evacuation and high enema.

Impacted hard stool on rectal examination – manual evacuation followed by sodium phosphate enema.
If the rectum is empty and impacted faeces is in the colon a high enema is given using 2 sodium phosphate enema administered with help of a nasogastric tube (14G).

Spurious Diarrhoea – Also known as overflow Diarrhoea or paradoxical Diarrhoea.
This occurs in:
- Patients with prolonged constipation who are given laxatives following which they start passing small amounts of loose or semi-loose stools at frequent intervals
- Elderly debilitated patients with reduced mobility or mostly bed bound

The patient usually gives a history of a prolonged period of constipation followed by laxative use or enema after which loose motions started, small quantities of watery stool at frequent intervals.

Management: Rectal examination
If hard stool present manual evacuation done
If only liquid stool or mucous present or rectum empty high enema given

Management of constipation in a colostomy patient

For these patients the same guidelines should be followed. However as there is no sphincter when giving an enema it can be retained by using a Foley's catheter for administration and keeping the bulb inflated for 10 minutes.
Ileostomy patients do not have constipation and should not be prescribed laxatives.

Experience in managing constipation in a homecare setting in India

- Constipation is a common symptom especially in patients taking opioids or if oral intake is poor, stool softeners like liquid paraffin and stimulants like bisacodyl and sodium picosulphate are prescribed and are effective in these patients.
- In patients with ≥5 days of constipation and no response to oral laxatives PR is done. If hard stool is present manual evacuation is done. If rectum is full of soft stool and oral laxatives have been ineffective, a sodium phosphate enema (180ml) is given. If the rectum is empty a high enema is given using 300-400ml of sodium phosphate enema.

REFERENCES

1. Symptom control –Constipation. www.palliativecareguidelines.scot.nhs.uk (10 November 2020).
2. Sykes NP. Constipation and Diarrhoea. In Hanks G et al (eds). Oxford Textbook of Palliative Medicine 5th ed. Oxford.OUP.p 675-85
3. Larkin PJ, Sykes, NP, Centeno C, Ellershaw JE, Elsner F, Eugene B, Gootjes JRG, Nabal M, Noquera A, Ripamonti C, Zucco F, Zuurmond WWA. The management of constipation in palliative care: clinical practice recommendations. Palliative Medicine (2008); 22: 796-807
4. Twycross, R., Wilcock, A., Howard, P. Palliative Care Formulary 5+. Nottingham. palliativedrugs.com. Drug Monographs- Gastro-intestinal system(pp. 38-107)
5. Fallon M, O'Neill B. ABC of palliative care. Constipation and diarrhoea.BMJ.1997; 315:1293-6.
6. Obokhare I. Fecal impaction: a cause for concern?. Clin Colon Rectal Surg. 2012;25(1):53-58.

C. DIARRHOEA

Diarrhoea is defined as the passage of 3 or more unformed stools in 24 hours with some variation from patient to patient. This symptom is less common as compared to constipation in the palliative care population.

Causes

Cancer and Cancer-related
Cancer of rectum, colon, pancreas (islet cell), carcinoid tumours, oat-cell lung carcinoma, pheochromocytoma, medullary carcinoma of thyroid, gastrinoma, fistula
Malignant bowel obstruction (subacute)
Faecal impaction (overflow/spurious Diarrhoea)
Cancer Treatment
Radiotherapy especially involving abdomen and pelvis
Chemotherapy
Surgery – gastrectomy, ileal resection, colectomy
Drugs and Diet
Drugs: laxatives, antibiotics, antacids, NSAIDs, iron preparations
Diet – fruits, spices and alcohol
Concurrent Disease

Inflammatory bowel disease- Crohn's disease, ulcerative colitis
Hyperthyroidism
Diabetes mellitus
Gastrointestinal Infection – Clostridium difficile, Escherichia coli, Salmonella

Assessment

History to determine the underlying cause of Diarrhoea:

- Frequency of bowel movements and duration of problem
- When was last normal bowel movement? Sudden onset of Diarrhoea following a period of constipation may be due to fecal impaction
- Stool consistency and presence of blood, mucus or pus
- Food and fluid intake in last few days
- Use of laxatives, antibiotics, proton pump inhibitors (PPIs)
- Recent chemotherapy
- Recent travel
- Previous bowel disease

Examination

Abdomen- to look for fecal masses, intestinal obstruction
Rectal examination- to exclude fecal impaction

Investigations

Abdominal x-ray erect- to confirm intestinal obstruction

Management

PREVENTION

- Probiotics should be prescribed along with antibiotics like Amoxycillin to prevent antibiotic-associated Diarrhoea.

NON-PHARMACOLOGICAL

- Rehydrate through oral route using solutions containing water, electrolytes and glucose (ORS, Electral).
- Lactose rich foods like milk should be avoided.
- Diet should consist of clear fluids and simple carbohydrates like bread and biscuits. Avoid high fat and protein foods. They can be gradually reintroduced when Diarrhoea begins to resolve.
- Give IV fluids for severe dehydration.

Treatment of Specific Causes

Drug-induced: laxatives, antibiotics, PPIs, NSAIDs – discontinue and review
Infection: Stool culture and appropriate antibiotics, for Clostridium difficile metronidazole is drug of choice.
Radiotherapy induced - Loperamide, diphenoxylate, cholestyramine, aspirin
Fecal impaction with overflow Diarrhoea - rectal measures- suppositories, enema, manual evacuation (follow constipation guideline).
Subacute bowel obstruction (follow malignant bowel obstruction guideline)
Gastrectomy, ileal resection, colectomy, bile acid Diarrhoea -Cholestyramine.
Carcinoid Syndrome – Octreotide.
Gastrinoma syndrome- PPI.
Fat malabsorption – Pancreatin enzyme replacement and/or PPI.
Fistula – Palliative surgery.

Pharmacological Management

LOPERAMIDE- an opioid, reduces peristalsis in the gut, increases water re absorption, and promotes fecal continence, making it a potent anti-Diarrhoeal agent. Because it only weakly crosses the blood-brain barrier, loperamide's side effect profile is more favorable than other opioids e.g. codiene, diphenoxylate.
Starting dose is 4mg followed by 2mg after each loose stool to a maximum dose of 16mg or 2mg qid. This can be increased to 4mg qid.

CODIENE AND DIPHENOXYLATE-If Diarrhoea persists switch to Codiene 30mg PO q6h or Tab Diphenoxylate 5-10mg q6h.
Octreotide- Costly, but effective with profuse secretory Diarrhoea seen in HIV disease, chemotherapy induced Diarrhoea, and those with high effluent volume from a stoma. It may be given via continuous subcutaneous infusion at a rate of 10 – 80 mcg every hour until symptoms improve.

REFERENCES

1. Symptom control –Diarrhoea www.palliativecareguidelines.scot.nhs.uk (6 December 2020).
2. Sykes NP. Constipation and Diarrhoea.In Hanks G et al (eds). Oxford Textbook of Palliative Medicine 5th ed. Oxford. OUP.p 675-85
3. Twycross, R., Wilcock, A., Howard, P. Palliative Care Formulary 5+. Nottingham.

palliativedrugs.com. Drug Monographs- Gastro-intestinal system(pp. 38-107)
4. Fallon M, O'Neill B. ABC of palliative care. Constipation and diarrhoea.BMJ.1997; 315:1293-6.
5. Blaabjerg S, Artzi DM, Aabenhus R. Probiotics for the Prevention of Antibiotic-Associated Diarrhoea in Outpatients-A Systematic Review and Meta-Analysis. Antibiotics (Basel). 2017;6(4):21. Published 2017 Oct 12.

D. MALIGNANT BOWEL OBSTRUCTION

Malignant bowel obstruction (MBO) occurs when there is failure of the forward movement of gastric or intestinal contents and can be due to mechanical obstruction (partial or complete) or peristaltic failure. It is a common complication in patients with advanced abdominal or pelvic malignancy and the highest incidence is found in ovarian and colorectal cancers.

Causes

i. Cancer: extrinsic- tumor growth, malignant adhesions
   intramural- tumor growth within muscle wall
   intraluminal- tumor growth within lumen

ii. Cancer treatment: adhesions, post-radiation fibrosis

iii. Drugs: cause motility disorders-opioids, anti-cholinergics

Assessment

Presenting symptoms vary according to site and degree of obstruction and involvement of other organs

Vomiting- in gastric, duodenal and small bowel obstruction vomiting occurs early, frequently and is large in volume while in large bowel obstruction it occurs later and maybe fecal in content

Nausea- maybe intermittent or continuous and often relieved by vomiting

Abdominal pain

Colicky pain- due to distension proximal to obstruction

Continuous pain- due to tumor and/or nerve infiltration

Abdominal distension- occurs due to accumulation of fluid and gas proximal to obstruction and is more common in large bowel obstruction

Constipation
Complete obstruction-no flatus/faeces
Partial obstruction- intermittent constipation

Examination
Hydration status
Abdominal distension
Abdominal masses
Rectal examination for fecal impaction

Investigations
Blood tests to exclude electrolyte abnormalities
Abdominal X-ray erect
Computed tomography abdomen can help decide choice of treatment

Management
Management depends on the type of obstruction, the patient's physical condition and preferences. Outcomes are improved by involvement of a multidisciplinary team consisting of surgeons, oncologists and the palliative care team as management could involve surgery, interventional procedures or pharmacological symptom management. Patients referred for home-based palliative care may have already been reviewed by surgeons and medical oncologists. Pharmacological symptom management is most commonly done in home besed palliative care.

Contraindications to Surgery
Presence of obstruction at multiple sites
Intra-abdominal carcinomatosis
Previous radiotherapy to abdomen or pelvis
Extensive distant metastases
Poor nutritional status
Poor performance status
Massive ascites rapidly re-accumulating after paracentesis
Patient's refusal to undergo surgery

General Care

Good oral care
Initially for 1-2 days may be kept nil orally and give SC fluids 1-1.5L/day
Small amounts of food and fluid as tolerated
In dehydrated patients give SC fluids 1-1.5L/day initially, if patient is not in dying phase.

Interventional Procedures

Stenting procedures
Venting procedures
NG tube drainage- may be done in homecare in patients with persistent vomiting not relieved with drugs

Pharmacological Management

The oral route of drug administration is often unreliable in MBO especially in presence of persistent vomiting so the SC, IV or TD route may be used for drug administration. In home-based palliative care SC route is most frequently used and may be managed by teaching the family caregivers to administer intermittent SC doses or CSCI doses of prescribed drugs. An individualized treatment plan should be devised considering goals of care and with agreement of palliative care team, patient and family. This should be reviewed and revised regularly.

Nausea and Vomiting
Antiemetics
Metoclopramide: It may be started initially if patient does not have colic
Starting dose 10mgtid PO or 10mg q8h SC or 30mg/24hrs CSCI
Increase to 20mg tid PO or SC (maximum dose - 120mg/24hrs)
Metoclopramide should be stopped if patient develops colic. Monitor for extrapyramidal side effects

Haloperidol: It may be given along with anti-secretory drugs
0.5-1mghsor q12hSCor 0.5-1mg/24hrs CSCI
Dose can be increased gradually to 5mg/24hrs.
A lower dose may be used in elderly patients. Be alert for extrapyramidal effects

5HT3 Antagonists
Ondansetron: May be used for vomiting where metoclopramide is contraindicated. Can be given with haloperidol and hyoscine butylbromide
Dose 4-8mg q8h PO or SC or 12-24mg/24hrs CSCI

Anti-secretory Drugs
Hyoscine butylbromide: Reduces intestinal motility and secretions and therefore colicky pain and vomiting. Started in patients with colic in whom metoclopramide is contraindicated
20mg q8h SC or 60mg/24hrs CSCI
Increase to 40mg q8h SC (maximum dose- 240mg/24hrs)
OR
Glycopyrrolate 0.1-0.2mg q8h SC

H2 Antagonists
Ranitidine helps by reducing gastric secretions and thus total GI secretions
Dose- 50mg bid SC

Octreotide: A somatostatin analogue, it reduces both GI secretions and motility thereby reducing colic and vomiting. It is more effective and faster acting than hyoscine but due to its high cost it should be used only when the latter is ineffective in controlling symptoms. It may also be used together with hyoscine.
Dose- 50-200mcg q8h SC or 150-600mcg/24hrs CSCI
A lower dose can be started in elderly patients

Corticosteroids: Steroids help in MBO through their anti-inflammatory effect which reduces tumor and bowel wall oedema. They are also thought to have an indirect analgesic effect through decreasing distension and a central anti-emetic effect. Therefore a trial of dexamethasone can be given.
Dose- 8-16mg SC od for 5-7days. If ineffective discontinue
If effective continue with reducing doses for 3-4weeks

Constipation
Rectal measures for a full rectum or fecal impaction
No laxatives for complete obstruction.

Pain

Continuous pain is managed according to WHO ladder and doses based on patient's prior analgesic requirements. NSAIDs, tramadol and morphine can be given PO, SC and IV and Fentanyl and Buprenorphine can be given TD.
Colicky pain- managed with hyoscine butylbromide

Managing malignant bowel obstruction in a homecare setting in India

Patients with subacute obstruction or in the absence of colicky pain are managed using metoclopramide 10mg tds, dexamethasone 8mg od and ranitidine 50mg bd administered as SC bolus doses which the family is taught to give. Pain is managed with diclofenac 50mg tds, and tramadol 50-100mg tds/qid also given as SC bolus doses. If a strong opioid is required fentanyl or buprenorphine transdermal patches are given. These patients usually have good symptom control.
In patients with colicky pain or if it develops after starting metoclopramide, hyoscine butylbromide, dexamethasone haloperidol and ondansetron are started as SC bolus doses. Pain management is the same in both situations.

REFERENCES

1. Symptom control –Bowel obstruction www.palliativecareguidelines.scot.nhs.uk (11 December 2020).
2. Ripamonti CI, Easson AM, Gerdes H. Bowel obstruction. In Hanks G et al (eds). Oxford Textbook of Palliative Medicine 5th ed. Oxford. OUP.p 919-29
3. Sykes, N., Ripamonti, C., Bruera, E., Gordon, D. Constipation, diarrhoea, and intestinal obstruction. In Fallon M, Hanks G (eds) ABC of Palliative Care 2nd ed. Oxford. Blackwell Publishing (pp. 29-35)
4. Franke AJ, Iqbal A, Starr JS et al, Management of malignant bowel obstruction associated with GI cancers. J Oncol Practice. 2017; 13:7, 426-34

E. ORAL CARE

Oral hygiene

Good oral hygiene is fundamental to the well-being of cancer patients. Its purpose is to:

- Keep lips and oral mucosa clean, soft and intact, as far as possible;
- Remove plaque and debris;
- Prevent oral infection, decay, periodontal disease, and halitosis;

- Relieve oral pain and discomfort and increase or maintain oral intake;
- Prevent further damage to the oral mucosa in patients undergoing antineoplastic and pharmacological treatments;
- Minimize psychological distress and social isolation and increase family involvement
- Maintain the patient's dignity even as death is approaching

Good Oral Care

- Good oral care should be part of the routine care of these patients
- Oral mucosa should be inspected daily
- Brushing teeth with a soft, small-headed toothbrush and fluoride toothpaste twice a day. If the patient has difficulty in swallowing non-foaming toothpaste should be used.
- Inter-dental cleaning with dental floss to remove debris between teeth not accessible with toothbrush
- Tongue cleaning with toothbrush or tongue scraper
- Those with a sore mouth can use a baby toothbrush or extra soft toothbrush
- Oral rinsing with a sodium bicarbonate solution (1/2 tsp baking soda in 200ml water) or sodium chloride solution (1/2 tsp salt in 200ml water) should be done 4-6 times a day especially after rising in the morning, after brushing and after every meal
- Lips should be kept lubricated with cream/vaseline/white paraffin
- In patients who are bedridden or unconscious the caregiver or nurse may use a damp gauze piece (soaked in tap water) wrapped round a gloved finger. This may also be used in those unable to tolerate a toothbrush.
- Patients should be encouraged to take a well-balanced diet and adequate fluid intake to keep mouth moist. Spices and foods which irritate the oral mucosa e.g. citrus fruits, should be used sparingly. Alcohol and tobacco should be avoided.

Denture hygiene

- Dentures may be cleaned outside the mouth with soap and water at least once a day. They must be rinsed under running water to remove large particles and then cleaned with a toothbrush to remove remaining debris. Toothpaste should not be used on dentures as it is abrasive and may damage the surface.
- The rest of the mouth and standing teeth should be cleaned separately
- Dentures should be removed at night. Plastic dentures should be soaked in a dilute sodium hypochlorite solution to disinfect them and thereby prevent denture stomatitis. Dentures with metal parts should be soaked in a chlorhexidine solution (0.12-0.2%) for disinfection.

- Those not having access to commercial products may soak dentures in a sodium bicarbonate solution.

Assessment for Oral Problems

History of previous dental or oral problems
History of dry mouth, loss of taste, halitosis, difficult or painful swallowing, speech difficulties
Current oral care plan
History of smoking
Treatment history- Recent or current radiotherapy to head and neck region and/or chemotherapy
Medication history
- opioids, anticholinergics, antidepressants, antiemetics, diuretics can cause dry mouth
- corticosteroids increase risk of candidiasis
- bisphosphonates increase risk of osteonecrosis of the jaw

Visual examination of oral cavity on every visit- examine lips, tongue, teeth, oral mucosa for presence of ulcers, mucositis, candidiasis, dental caries, tongue coating
Assess for pain
Assess patient's ability for self-care
Dental opinion if necessary

Management of common oral problems

ORAL MUCOSITIS:

Oral mucositis refers to the erythematous and ulcerative lesions of the oral mucosa seen in cancer patients receiving chemotherapy, and/or radiotherapy to areas involving the oral cavity. It is very common in head and neck cancer patients undergoing radiotherapy or concurrent chemoradiation. Oral mucositis is often very painful leading to difficulty in eating, swallowing and speech. It also compromises oral hygiene with increased risk for local and systemic infection and may lead to a need for enteral/ parenteral nutrition, increased opioid use and interruption of cancer treatment.

Assessment

History: Onset within 5-14 days after chemotherapy and/or radiotherapy to oral cavity
Examination of oral cavity: Erythema, erosion and patchy or confluent ulceration which often has a superficial pseudomembranous membrane.

Severity of Mucositis

WHO Scale

Grade 0: No Mucositis
Grade 1: Erythema and soreness
Grade 2: Ulcers, able to eat solids
Grade 3: Ulcers, requires liquid diet (due to mucositis)
Grade 4: Ulcers, alimentation not possible (due to mucositis)

Prevention and Management

Prevention

- Good oral care as outlined above using extra soft or baby toothbrush and frequent non-medicated oral rinses (soda bicarbonate and/or saline oral rinses 4 times a day).
- Education of patients and/or caregivers on need of following good oral care.
- Avoid alcohol and tobacco.
- Patient should minimize incidental mucosal trauma by avoiding rough and sharp foods.
- Benzydamine mouthwash tds in H&N patients undergoing moderate RT (<50 Gy) or chemo-radiation is effective in reducing incidence of OM. Benzydamine reduces intensity and duration of oral mucositis in all H&N patients undergoing RT and/o chemo-radiation.
- Oral cryotherapy (cooling the mouth using cold water, ice chips or cubes or ice cream) constricts blood vessels of oral mucosa and reduces severity of oral mucositis due to chemotherapy agents. This should be done 30 minutes before chemotherapy administration.
- Chlorhexidine mouthwash and sucralfate should not be used for prevention of oral mucositis in H&N patients undergoing RT. They have no prophylactic value.

Management

Oral mucositis is very painful leading to difficulty in eating, swallowing and speech. It is therefore important to manage the pain and other problems associated with it.

- 2% viscous lignocaine oral rinse before meals decreases the pain and enables the patient to eat.
- Oral pain can be managed with 0.2% morphine mouthwash in H&N patients receiving chemoradiation. Benzydamine mouthwash also helps in reducing the pain.
- Drugs may be prescribed according to WHO pain ladder and for severe oral pain, oral morphine may be prescribed.

When swallowing is difficult, depending on severity, semisolid or liquid diet may be advised. When mucositis is severe (WHO Grade 4) and oral intake is not possible, nasogastric tube or PEG tube is advised.

Oral Pain

Causes- mucositis, angular stomatitis, oral malignancy, aphthous ulcers, trauma

MANAGEMENT

Treat the cause
Benzydamine mouthwash three times a day may relieve pain
Choline salicylate gel applied locally to painful area/ulcer
Mouth may be rinsed with xylocaine viscous about 15 minutes before meals to decrease pain while eating
0.2% morphine mouthwash can be used for pain due to oral mucositis
For severe pain in oral mucositis systemic analgesics may be used according to WHO Analgesic Ladder (see pain management guideline)

Drymouth (xerostomia)

Occurs due to a reduction in salivary secretions or a change in saliva composition or both which may be is caused by radiotherapy to head and neck region, chemotherapy, tumor infiltration, dehydration, drugs (opioids, antidepressants, anticholinergics, anti-emetics, anti-psychotics, diuretics). Xerostomia leads to difficult and painful swallowing and speech difficulty. It also increases the occurrence of infections like oral candidiasis.

MANAGEMENT

Treat reversible causes (review medications)

Non-pharmacological measures

- Good oral care
- Gently remove coatings, debris and plaques from lips, tongue and mucosa with damp gauze
- Saline or sodium bicarbonate mouthwashes to clean mouth
- Application of petroleum jelly/coconut oil on lips
- Frequent sips of water/fluid
- Patient can suck ice chips/frozen pineapple pieces
- Saliva stimulation with sugar-free chewing gum- Chewing gum increases salivary flow mainly by stimulation of chemoreceptors in the mouth (taste effect) and is effective in treating xerostomia

PHARMACOLOGICAL MANAGEMENT

1. Saliva substitutes may be used but these products may be expensive (Wet mouth, Biotene dry mouth). They usually contain carboxymethylcellulose and a mucin base. They should be used before meals and at bedtime, according to the patient's need.
2. Pilocarpine 5-10mg tid PO- Start with 5mg. Effective in xerostomia due to drugs or radiotherapy.

Side effects: Sweating, bronchospasm, increased urinary frequency, diarrhoea, hypotension and bradycardia.
Due to cholinergic effects contraindicated in asthma, COPD, glaucoma, heart failure, hyperthyroidism, gastric ulcer and Parkinson's disease.

Candidiasis

Candidiasis is the most common oral infection in palliative care. Dry mouth, dentures and topical steroid use make patients susceptible to the infection.

The common types of oral candidiasis are pseudomembranous (white spots or plaques in oral cavity), erythematous (red, inflamed area on mucosa), denture stomatitis, (inflamed area on hard palate) and angular cheilitis (cracking or inflammation at angles of mouth). Oral candidiasis may spread locally to oesophagus or more widely to cause systemic candidiasis.

MANAGEMENT
Treatment of predisposing factors
Good oral hygiene
Clotrimazole oral paint 0.1% applied locally tid x 7-14 days
Fluconazole 50-200mg od PO x 7-14 days
Itraconazole 100-200mg od PO x 7-14 days

Halitosis

Halitosis may be physiological (no underlying disease present), or pathological (underlying disease present). Physiological halitosis is more common and usually occurs due to the bacterial putrefaction of food, epithelial cells, blood cells and saliva on the dorsum of the tongue. Pathological halitosis usually results from disease of the oral cavity. It may also occur due to respiratory and gastrointestinal tract disease or a systemic metabolic problem.

MANAGEMENT
Treat reversible causes (oral infection in oral cancer treated with metronidazole)
Good oral care, fluid intake
Regular rinsing of mouth with sodium bicarbonate solution or a mouthwash like chlorhexidine
Dietary modification-
Smoking cessation

Taste disturbance

Taste disturbance occurs in 44-50% of patients with advanced cancer and is more frequent in head and neck cancer patients especially those who have been treated with radiotherapy. Other causes for taste disturbance could be chemotherapy, oral surgery, oral problems like infections and xerostomia, poor oral hygiene, drugs, malnutrition and zinc deficiency.

MANAGEMENT
Treat underlying causes (treatment of oral infections, xerostomia)
Good oral hygiene
Dietary interventions
- Nutritional intake needs to be maintained and patients may try different foods and choose according to their taste
- The taste of food can be improved using various flavouring agents
- -The food should be presented in an attractive manner while also focusing on smell, consistency and temperature

Zinc supplements

Sialorrhoea and Drooling

Excessive drooling is often not related to sialorrhea (excessive saliva production) but is due to difficulty in holding saliva in the mouth because of facial weakness or deformity and/or removing saliva from the mouth due to dysphagia.

MANAGEMENT
Good oral care
Positioning of head
Speech therapist may be consulted for advice on swallowing techniques
Anticholinergic drugs- Tab Glycopyrronium 0.5-1mg tid PO
Tab Amitriptyline 10-25mg hs

Tenacious saliva

MANAGEMENT

Treat reversible causes (dehydration)
Good oral care
Frequent sips of water/fluid
Rinsing with sodium bicarbonate solution
Dietary modifications

- Fruit juices like pineapple and dark grape should be encouraged
- Milk and caffeine should be avoided

ORAL CARE AT THE END OF LIFE

It is important to involve families in caring for patients at the end of life and oral care is an important part of this care providing comfort and improving quality of life.

Management

- Oral hygiene should be maintained.
- Teeth and dentures should be cleaned.
- Medications that might cause dry mouth could be changed or stopped.
- The mouth should be hydrated to prevent the discomfort of dry mouth - the patient's mouth should be moistened every hour with sips of water given with a spoon or dropper or by applying a wet sponge stick. Vaseline or oil may be used on the lips to prevent drying/cracking. Oil, butter or *ghee* may also be applied inside the mouth.
- Families and friends should also be made aware of the mouth care regime at the end of life to ensure they can support the patient and have greater involvement in their last days of life.

REFERENCES

1. Bagg J, Davies A. Oral health in patients with advanced disease. In Fallon M, Hanks G (eds) ABC of Palliative Care 2nd ed. Oxford. Blackwell Publishing (pp. 17-20)
2. Davies AN. Oral care. In Hanks G et al (eds). Oxford Textbook of Palliative Medicine 5th ed. Oxford. OUP.p 447-56
3. ChandelS, Khan MA, Singh N, Agrawal A, Khare V. The effect of sodium bicarbonate oral rinse on salivary pH and oral microflora: A prospective cohort study. Natl J Maxillofac Surg. 2017; 8:106-9
4. Farah CS, McIntosh L, McCullough MJ. Mouthwashes. AustPrescr 2009;32:16

5. Madeswaran S, Jayachandran S. Sodium Bicarbonate: review and itsuse in dentistry. Ind J Dent Res. 2018; 29:5, 672-
6. Murphy BA, Zatarain LA, Cmelak AJ et al. Palliative issues in the care of patients with cancer of the head and neck. In Hanks G et al (eds). Oxford Textbook of Palliative Medicine 5th ed. Oxford. OUP.p
7. Elad S, Fong Cheng KK, Lalla RV et al. MASCC/ISOO clinical practice guidelines for the management of mucositis secondary to cancer therapy. Cancer. 2020;126(19):4423-4431.
8. Peterson DE, Boers-Doets CB, Bensadoun RJ, Herrstedt J. Management of oral and gastrointestinal mucosal injury: ESMO clinical practice guidelines for diagnosis, treatment and follow-up. Sup & Palliat Care. 2015; 26(5):V139-V151
9. Riley P, Glenny AM, Worthington HV, Littlewood A, Clarkson JE, McCabe MG. Interventions for preventing oral mucositis in patients with cancer receiving treatment: Oral cryotherapy. Cochrane Database Syst Rev 2015;12:CD011552.
10. Owlia F, Kazemeini SK, Gholami N. Prevention and management of mucositis in patients with cancer: a review article. Iran J Cancer Prev. 2012;5(4):216-220.
11. Nicolatou-Galitis O, Bossi P, Orlandi E et al. The role of benzydamine in prevention and treatment of chemoradiotherapy –induced mucositis.Supp Care Cancer.2021. https://doi.org/10.1007/s00520-021-06048-5
12. Lalla RV, Sonis ST, Peterson DE. Management of oral mucositis in patients who have cancer. Dent Clin North Am. 2008;52(1):61-viii.
13. Barbieri T, Costa KC, Guerra LFC. Current alternatives in the prevention and treatment of xerostomia in cancer therapy. Rev GaúchOdontol. 2020;68:e20200016.

F. ANOREXIA/CACHEXIA

Anorexia is the loss or absence of the desire to eat resulting in reduced caloric intake and weight loss and **cachexia** is a multiorgan syndrome defined by weight loss, muscle mass loss (with or without fat loss) and inflammation.

Anorexia is present in 13-55% cancer patients at diagnosis and in approximately 65% of those who are terminally-ill. Weight loss at the time of cancer diagnosis varies according to cancer site and is most common in head and neck, oesophageal, gastric and pancreatic cancers.

The **cancer anorexia-cachexia syndrome** is a complex metabolic syndrome characterized by weight loss, muscle wasting, anorexia and weakness which affects functional status. It adversely impacts quality of life causing distress to both patients and caregivers.

The anorexia-cachexia syndrome is also observed in other palliative care conditions like AIDS and end-stage heart failure and renal failure.

Causes of cancer cachexia can be divided into 2 groups, primary and secondary.

Primary cachexia is caused by tumour-induced metabolic changes-

- Tumor products secreted which disturb tissue repair, accelerate catabolism and slow anabolism leading to tissue loss
- Cancer causes systemic inflammatory response- Increases metabolic rate and secretes products leading to early satiety and loss of appetite.

Secondary cachexia is caused by factors that result in poor dietary intake which leads to malnutrition:

- Dysphagia, odynophagia
- Altered taste or smell
- Early satiety, gastric stasis, delayed gastric emptying
- Dyspepsia
- Sore mouth,
- Nausea, vomiting, constipation
- Malodour
- Bowel obstruction
- Metabolic abnormalities- hypercalcemia, hypernatremia
- Infections
- Treatment related-
    a. Chemotherapy and radiotherapy-related side effects e.g. mucositis, nausea, vomiting, diarrhoea
    b. Radical surgery e.g. gastrectomy
- Psychological issues – depression, anxiety, loneliness

Assessment

The aim is to identify anorexia/cachexia at an early stage

Detailed patient history and examination

- Body weight- >5% unintentional weight loss in preceding 6 months is associated with cancer cachexia
- Food intake recall- anorexia and/or reduced food intake
- History of increased fatigue
- Mid-arm circumference
- Karnofsky's performance score

Management

- Management should be individualized based on the stage of the disease, patient's and family's wishes and risks and benefits of treatment
- Treat reversible causes that decrease food intake– symptoms like pain, nausea, vomiting, constipation, metabolic abnormalities, infections
- Non-pharmacological management
- Pharmacological management
- If there are signs and symptoms of dehydration, consider administering SC fluids
- Enteral feeding can be considered if there is dysphagia and patient experiences hunger
- Total parenteral nutrition should b avoided as it has not found to provide any benefit
- Non-pharmacological measures
- Advise patient to take small, frequent, nutrient dense meals according to preference and capacity to eat
- Force feeding should be discouraged
- Explain that loss of appetite along with a gradual reduction in oral intake is a natural part of the disease process
- Explain that IV fluids will not improve appetite or change course of disease

Pharmacological measures

The following medications have limited or temporary benefit but should be considered as they may improve quality of life. They also have significant side effects which need to be considered before prescribing.

CORTICOSTEROIDS

- **They improve appetite, provide a sense of wellbeing and also have an antiemetic effect. The onset of effect is rapid but usually lasts only for 3-4 weeks**
- **Dexamethasone-** starting dose 2-4mg od PO in the morning or Prednisolone- staring dose 30mg od PO in the morning
- Prescribe for a week initially. If there is no effect within 5 days discontinue. If helpful gradually reduce to minimum effective dose
- Also prescribe gastro-protective drugs (ranitidine or omeprazole)
- Assess and review dose regularly.
- Corticosteroids are not suitable for long term use. There is loss of efficacy after 4-6 weeks and increase in side effects like proximal myopathy.
- Side effects include Cushing syndrome, hyperglycemia, adrenal insufficiency, myopathy, peptic acid disease, insomnia, infection risk and neuropsychological effects.
- Corticosteroid use is discouraged with many new immunotherapies (eg, ipilimumab, nivolumab, pembrolizumab).
- Prokinetics
- These are used for delayed gastric emptying, gastric stasis and nausea and vomiting
- Metoclopramide 10mg tid PO before meals
- Domperidone 10mg tid PO before meals

PROGESTOGENS E.G. MEGESTROL

- May stimulate appetite and weigh gain in cancer patients
- Onset of action may take a few weeks but effect is more prolonged than steroids so should be prescribed for patients with a longer prognosis

MEGESTROL ACETATE

- Starting dose: 80-160mg PO daily
- If initial response is poor, double the dose in 2-3 weeks
- Maximum dose: 800mg/24 hours
- For appetite stimulation lower dose is as effective as higher dose but for weight gain the effect seems to be dose dependent.
- Side effects include nausea, oedema and thromboembolism

COMBINATION WITH NSAIDS

The inflammatory response in primary cachexia may be decreased by adding NSAIDs to megestrol. Ranitidine or omeprazole should be added as a gastroprotective

- Megestrol Acetate 160mg tid + Ibuprofen400mg tid
- Megestrol Acetate 160mg bd + celecoxib 200mg daily

Experience in the homecare setting in India

- The patient's loss of appetite is very distressing for the family members and educating them not to force feed and give small meals is very important
- Treating oral infections like thrush and providing good oral care helpful
- Dexamethasone PO is often effective in improving appetite and is given a trial in most patients if they are not in the terminal phase. Doses as low as 2mg/day may be effective.
- Megestrol is costly and is therefore less frequently prescribed.

REFERENCES

1. Nicolini, A., Ferrari, P., Masoni, M.C., Fini, M., Pagani, S., Giampietro, O., Carpi, A. Malnutrition, anorexia and cachexia in cancer patients: A mini-review on pathogenesis and treatment. Biomedicine & Pharmacotherapy (2013); 67: 807-817
2. Muliawati Y, Haroen H,, Rotty LW. Cancer anorexia cachexia syndrome. Acta Med Indones. 2012; 44(2): 154-62
3. Twycross R, Wilcock A. Introducing palliative care. 5th Ed. Calicut. palliativedrugs. com. pp 233-57
4. Inui A. Cancer Anorexia-Cachexia Syndrome: Current Issues in Research and Management. CA Can J Clin.2002; 52(2):72-9
5. Fearon K, Barber M. Anorexia, cachexia, nutrition and fatigue. In Fallon M, Hanks G (eds) ABC of Palliative Care 2nd ed. Oxford. Blackwell Publishing. 2006 (pp. 21-24)

G. HICCUPS

Hiccup is a pathological respiratory reflex characterized by spasm of one or both sides of the diaphragm, resulting in sudden inspiration and closure of the glottis. Accessory muscles of respiration (anterior scalene, intercostal, abdominal) are occasionally involved.

Occasional hiccup is such a common human experience that it only warrants designation as a symptom when it is severe and intractable. It shows a circadian rhythm, being more common in the evening.

Hiccups can be classified as transient (usually lasting a few minutes and can be intermittent) for which non-pharmacological measures may be used, persistent (last for more than 48 hours) and intractable (lasts for more than a month). Pharmacological measures are usually required for persistent and intractable hiccups.

Causes of hiccups in palliative care:

Gastrointestinal- gastric distension and stasis, gastro-oesopageal reflux
Diaphragmatic irritation
Infections
CNS pathology- tumor, metastases, stroke
Metabolic disturbances- uraemia, hypocalcemia, hypokalemia
Drugs- steroids, benzodiazepines, opioids

Assessment

The aim of assessment should be to determine the cause of hiccups
Review existing medications before adding more drugs to manage hiccups

Management

Treat reversible causes- treat infections, reverse metabolic disturbances.
Treat symptomatically as cause is often multifactorial in palliative care.
Non-pharmacological management should always be tried first due to potential side effects of drugs.
Drugs should only be used for persistent hiccups after trying non-pharmacological measures.

Non-pharmacological Management

Vagal nerve stimulation – drinking water, forcible traction of tongue, Valsalvamanoeuvre

Interruption of respiratory cycle (increasing $PaCO_2$) – breath holding, hyperventilating, re-breathing from a paper bag
Counter irritation to the diaphragm- pulling knees up to chest and leaning forward to compress the chest.

Pharmacological Management

A number of drugs have been used in management of hiccups but there is limited research to guide drug choice.

Metoclopramide- dopamine antagonist
Effective in treating hiccups due to all causes but especially due to gastric distension and stasis
Dose: 10-20mgtid PO x 5 days and review
Side effects: extrapyramidal effects
Lower starting dosein elderly patients

PPIs may be effective in hiccups caused by reflux
Omeprazole- 20mg bid PO

Baclofen– a GABA receptor agonist, muscle relaxant
Dose: 5mg bid to 20mg tid PO x 3-5 days
Review after 3 days
Main adverse effects: drowsiness, dizziness
Use with caution in renal failure, active peptic ulcer disease

Gabapentin- blocks neural calcium channels and increases GABA release. It is effective in hiccups with central aetiology.
Dose: 300-400mg tid PO
Start at with 300mg hs and increase dose every 2-3 days till 300mg tid. Increase to a maximum dose of 400 mg tid

Haloperidol- has been found to be effective because of its dopamine antagonist action.
Dose range: 1.5mg tidPO
Review after 3 days

Chlorpromazine- This is no longer drug of first choice due to side effects. May be prescribed if there is limited or no response to metoclopramide and baclofen
Dose- 25-50mg tid PO x 3 days and review

Midazolam- This may be the most appropriate drug for management of hiccups in the last days of life as it is also used for managing agitation and distress in this phase of life.
Dose: 2.5mg SC, repeated every 15 minutes until resolution of hiccups, but without causing excessive sedation.

REFERENCES

1. Jeon YS, Kearney AM, Baker PG. Management of hiccups in palliative care patients. BMJ Supportive & Palliative Care. 2018; 8:1-6
2. Woelk CJ. Managing hiccups. Can Fam Physician. 2011;57(6):672-e201.
3. Clark K. Dysphagia, dyspepsia and hiccups. In Hanks G et al (eds). Oxford Textbook of Palliative Medicine 5th ed. Oxford. OUP.p 651-660
4. Zhang C, Zhang R, Zhang S, et al. Baclofen for stroke patients with persistent hiccups: a randomized, double-blind, placebo-controlled trial. Trials. 2014;15:295
5. Wang T, Wang D . Metoclopramide for patients with intractable hiccups: a multicentre, randomised, controlled pilot study. Intern Med J 2014;44:1205–9.

H. ASCITES

Ascites is the accumulation of free fluid in the peritoneal cavity.

Causes of Ascites

Malignancy is the cause in approximately 10% of all cases of ascites and about 15- 50% of cancer patients will develop ascites. Ascites most commonly occur in gastrointestinal and ovarian cancers.
Non-malignant causes of ascites include liver disease, congestive cardiac failure, nephrotic syndrome, pancreatitis, tuberculosis and bowel perforation.
Ascites is associated with a poor prognosis

Assessment

SYMPTOMS
Abdominal discomfort, feeling of fullness, pain
Loss of appetite, acid reflux
Nausea and vomiting
Breathlessness
Insomnia due to discomfort

SIGNS
Increased abdominal girth
Fluid thrill, dullness in flanks on percussion
Pedal oedema

INVESTIGATIONS
USG abdomen should be done to confirm presence of ascites especially if there is a doubt clinically.

Management of malignant ascites

Diuretic therapy must be tried in all patients with malignant ascites having a prognosis of more than 4 weeks.
Spironolactone is the diuretic of choice and acts by competitively blocking aldosterone leading to an increase in sodium excretion. It is a potassium sparing diuretic.
Dose- 100-400mg/day PO
Start with 100mg and increase dose every5-7 days in increments of 50-100mg till maximum dose of 400mg is reached. Dose should be titrated according to individual response.

In elderly patients starting dose should be smaller-50mg
Side effects- Nausea, headache, lethargy, delirium, hyperkalaemia, skin rashes, diarrhoea and hyponatraemia.

LOOP DIURETICS

Furosemide or Torsemide may be given along with spironolactone for a better response.
Dose
Furosemide: 40-80 mg/day +Spironolactone 50-100mg/day
Torsemide: 5-10mg/day+Spironolactone 50-100mg/day

THERAPEUTIC PARACENTESIS

Some patients who have malignant ascites have mild symptoms or are asymptomatic. In such patients paracentesis should not be done as invasive procedures may add to the patient's distress and symptom burden.

Not all patients with ascites respond to diuretics and paracentesis is commonly done to relieve distressing symptoms.

Paracentesis may be done safely in the homecare setting. It is especially useful in the last weeks of life when patients are unwilling/unable to go to hospital and need relief from distressing symptoms.

- Written informed consent should be obtained before the procedure.
- The bladder should be emptied before starting the procedure
- Under aseptic conditions a wide bore venous catheter or venflon (No 18/20) may be used.
- It is connected to a urobag through a sterile IV drip set.
- The amount of fluid removed during the procedure varies and upto 5L may be removed during a single paracentesis
- Blood pressure should be monitored before and during and after the procedure. If there is hypotension IV fluids may be given or the procedure may be discontinued.
- There is no evidence to support the use of albumin infusions before or after the procedure. The use of IV fluids is also not recommended.
-

Ascitic fluid may re-accumulate after a few days and the procedure may have to be repeated when symptoms recur.

Due to re-accumulation of ascitic fluid a pigtail catheter may be introduced into the abdominal cavity. This catheter may remain in situ for a period of time and ascitic fluid may be drained repeatedly through this whenever it accumulates.

Managing Ascites in the homecare setting in India

For patients who have distressing symptoms due to ascites paracentesis is done at home under asepsis. This is done especially in those patients who are unable or unwilling to go to hospital, usually in the last weeks of life. Diuretic therapy is tried in most patients using a combination of furosemide 20mg and Spironolactone 50mg or Torsemide 5mg and spironolactone 50mg. This is effective in some patients and repeated paracentesis may be avoided.

REFERENCES

1. Twycross R. Symptom management:alimentary. Introducing palliative care. 5th Ed. Calicut. palliativedrugs.com. pp101-44
2. Keen J. Jaundice, ascites and encephalopathy.In Hanks G et al (eds). Oxford Textbook of Palliative Medicine 5th ed. Oxford. OUP.pp 686-701

Urinary Tract Symptoms

INTRODUCTION

Palliative care patients may face urinary problems even if primary pathology is not urological origin. Problems occur due to advanced malignancy, chronic illness, neurodegenerative disease, prior radiation, chemotherapy or surgery.

i. **Urinary Incontinence (UI)** is loss of bladder control causing urine to leak. It is a common problem near the end of life when functional decline occurs. It has a significant impact on the patient's dignity and self-esteem and is associated with a decreased quality of life.
   UI can be further defined according to patient's presentation and symptoms.
ii. **Stress urinary incontinence (SUI)** is the involuntary loss of urine associated with physical exertion or increased intra-abdominal pressure .g. sneezing, coughing and laughing.
iii. **Urge urinary incontinence (UUI)** is the involuntary loss of urine accompanied or preceded by a strong desire to void or urgency.
iv. **Mixed urinary incontinence (MUI)** has features of UUI and SUI.
v. **Overflow incontinence (OFI)** is caused when the bladder is full and there is inability to fully empty it causing urine to leak. It occurs due to hypotonic bladder or bladder outlet obstruction secondary to tumor, stricture or prostate hyperplasia
vi. **Overactive bladder (OAB)** - This term is often used to describe UI and comprises the symptoms of urgency, frequency and nocturia with or without UUI

CAUSES

UI is common in the elderly and in those with advanced diseases at the end-of-life
In the elderly age-related changes to urinary tract may contribute to UI (detrusor overactivity, impaired bladder contractility, decreased pressure in urethra closure, atrophy of urethral areas, and prostatic hypertrophy).

It may be as a result of lesions in sacral spinal cord, higher micturation centres or other neurological lesions.
It may be associated with cerebrovascular disease, multiple sclerosis, Parkinson's, Alzheimer's.

Constipation, UTI, drugs reduced mobility, lack of easy access to a bathroom may also cause or worsen UI
Possible reversible causes are constipation, UTI and drugs

ASSESSMENT

History – Symptoms of SUI (leaking of urine associated with coughing, sneezing an), OFI (nocturia, dribbling, difficulty in initiating a urine stream) and UTI
Determine duration of symptoms and probable cause. UI of recent onset may be due to exacerbation of pre-existing symptoms e.g. constipation which has worsened
Review of medications (diuretics, benzodiazepines, antipsychotics) and comorbidities
Depending on patient's general condition evaluation may be done to rule out reversible causes.

MANAGEMENT

Treat reversible causes- Constipation, UTI. If possible change drugs or reduce doses

NON-PHARMACOLOGICAL

This should always be tried first
The patient may be taught pelvic floor exercises (Kegel's exercises) which strengthen and retrain the bladder muscle to regain some control over urinary function. They are most effective in SUI and may also help in MUI. They are less effective in UUI.
-Increased physical activity if possible.

- Timed voiding, habit retraining – improvement in daytime voiding.
- Adult diapers may be advised according to willingness and comfort of patient
- Incontinence pads and underwear (expensive so suitable for those who can afford)

PHARMACOLOGICAL

SUI- Tab Duloxetine 20mg bd PO; May be increased to 40mg bd after 2 weeks
Side effects- dry mouth, dizziness, nausea, constipation, insomnia, sweating, headache
Contraindications- severe renal and hepatic failure

UUI–Tab Oxybutynin 2.5-5mg PO bd or tds; maximum dose- 5mg qid
Tab Tolterodine IR 1-2mg bd or ER 2-4mg od
Side effects- dry mouth, drowsiness, dizziness, confusion, constipation, dry eyes, headache, tachycardia
Contraindications – Dementia, delirium

An indwelling catheter may be advised when pharmacological or non-pharmacological treatment is ineffective or inappropriate. Condom catheter may be advised alternatively in males.

b. Urinary retention

Urinary retention may occur either because of an under active bladder muscle, bladder outlet obstruction, or a combination of both. There is incomplete bladder emptying which worsens storage symptoms, causes recurrent UTIs and may even cause impairment of kidney function.

Causes: Outlet obstruction – Clot retention, tumor
Patients at the end-of-life when functional decline decreases

ASSESSMENT

History

MANAGEMENT

When managing patients with urinary retention the aims are adequate bladder emptying, prevention of UTI and preservation of kidney function.

Long-term indwelling urinary catheters and clean intermittent self-catheterization both achieve this goal but long-term indwelling catheters have a greater incidence of complications like repeated UTIs, blockages and encrustations. Therefore the gold standard of managing urinary retention is CISC and patients and caregivers should be motivated to learn this procedure.

CLEAN INTERMITTENT SELF-CATHETERIZATION (CISC)

CISC is defined as the repetitive temporary placement of a catheter to empty the bladder

Indications

1. Neuropathic Bladder (Multiple Sclerosis, Spinal Cord Tumour and Injury, Transverse Myelitis).
2. Acontractile Bladder.

Frequency of Catheterization

At least four times a day and more frequently in those with high fluid intake or small capacity bladder

In order to remain dry patients have to balance fluid intake and frequency of catheterization

Teaching CISC at home

Explain the reasons and benefits of the procedure

Reassure patient and/or caregiver that self-catheterization is not painful, difficult or dangerous.

Materials needed

- Soap and water
- Lubricant – Xylocaine 2% Jelly
- Polyvinyl chloride (Nelaton) catheter No. 12 or 14
- Container/urinal to collect the urine

Procedure

- Wash hands thoroughly with soap and water
- Wash catheter with water
- After washing hands and catheter please do not touch any contaminated area.
- Position:

  Females-sitting with feet on chair, lower limbs flexed and knees parted. Mirror may be placed in front initially in order to visualize the perineum

  Males - sitting/standing
- Wash the perineal area/penis with soap and water
- Hold the catheter 2 cm from the tip, lubricate the tip with 2% xylocaine jelly and allow it to spread along the catheter
- Gently introduce the catheter into the urethral meatus

  In females about 5-10cm

  In males about 15-20cm (keep the penis perpendicular to the surface of the abdomen)-If any resistance is felt, hold firm and gently push until muscles relax and the catheter passesthrough
- Once the urine starts to flow out push the catheter in for 2cm more
- Empty the urine into the container/urinal
- Once urine has stopped flowing rotate the catheter and apply suprapubic pressure.

- Then withdraw the catheter slowly. If urine starts to drain during withdrawal, hold the catheter at that level until the urine stops flowing.
- Remove the catheter once the urine flow stops
- Clean and store the catheter

Intermittent Catheterization by Caregiver

Caregivers can be taught to do intermittent catheterization for patients who are unable to carry out the procedure themselves due to various reasons e.g. debility, poor vision, poor hand-eye coordination and hand tremors.

Care of the catheter

- After use, immediately wash the outer surface of the catheter with soap and water and rinse the inside with clean water
- Shake out the water from inside the catheter, air dry it and story in a clean container
- The catheter may be reused until is damaged, deformed or discolored
- Reusing a catheter does not result in a greater incidence of UTI

c. Hematuria

COMMON CAUSES

Bleeding from urinary tract tumor
Post pelvic irradiation
Urinary tract infection (UTI)
Clotting disorders
Leukemia

ASSESSMENT

Detailed history to identify cause of bleeding- history of tumor, radiotherapy chemotherapy
Assess severity of bleeding in order to determine whether it is life-threatening or may be controlled with specific measures
History of pain related to hematuria
Review the need of drugs that may increase bleeding-NSAIDs, anticoagulants, aspirindistended bladder
Examination- abdominal masses,
Investigations- Urine routine, microscopy and urine culture/sensitivity if UTI suspected

MANAGEMENT

In patients where hematuria can be expected as in a bladder tumor discuss this with the patient and/or family

A UTI causing hematuria may be treated with antibiotics

For mild hematuria encourage the patient to increase fluid intake

For moderate to severe hematuria bladder irrigation with cold normal saline

REFERENCES

1. Demaagd GA, Davenport TC. Management of urinary incontinence. P T. 2012;37(6):345-361H.
2. Panesar K. Drug-induced urinary incontinence. US Pharm. 2014;39(8):24-29
3. Gray, M. and Sims, T. (2015). Urinary Tract Disorders. Oxford Textbook of Palliative Nursing (pp. 262-278)
4. Narayanaswamy A. Clean intermittent self-catheterisation – principles and practice. Ind J Urol(2000) 17: 1-5

Other Symptoms

A. PRURITUS

Introduction

Pruritus or itch can be described as an unpleasant sensation of the skin that provokes the desire to scratch or rub. It is an uncommon symptom but when it occurs it causes a lot of discomfort, irritability, frustration, anxiety and depression, insomnia and adversely affects the patient's quality of life.

Causes of pruritus in advanced disease are:

Dermatological- Dry skin, scabies, lice, atopic dermatitis, contact dermatitis,urticaria, lichen planus, psoriasis, insect bites

Systemic

- Biliary and hepatic disease - Cholestatic jaundice, hepatitis, primary biliary cirrhosis
- Uraemia (chronic renal failure)
- Haematological disorders –iron deficiency anaemia, polycythaemiavera, leukaemia, lymphoma, multiple myeloma
- Medications – opioids, selective serotonin re-uptake inhibitors (SSRIs), ACE inhibitors, statins, chemotherapeutic drugs, monoclonal antibodies
- Infectious diseases – HIV, syphilis, parasitic, fungal, viral
- Malignancies – Breast, lung, carcinoid syndrome
- Endocrine disorders – diabetes mellitus, thyroid dysfunction, parathyroid disease
- Neurological disorders - brain tumors, multiple sclerosis, stroke, brain injury
- Psychogenic

Assessment

Detailed patient history including severity of itch and how it has affected patient's quality of life like disturbed sleep.
Medication review.
Examination of skin to determine local and systemic causes.

Investigations (If appropriate)

Complete blood count, serum ferritin, kidney function tests and electrolytes, liver function tests, blood glucose, thyroid function tests, C-reactive protein, skin biopsy

Management

CORRECT THE CORRECTABLE

- Where possible treat underlying cause e.g. if cholestatic jaundice is the cause bile duct stenting may done if appropriate
- Review medications likely to be the cause of pruritus and prescribe an alternative e.g. if itching is due to an opioid consider changing it

NON-PHARMACOLOGICAL MEASURES

Treating dry skin and general skin care measures are helpful for all patients and they and the caregivers must be educated on this

- May use mild soap but talcum powder should be avoided
- Emollients should be used liberally on skin .They should be free of alcohol and fragrance
- After bathing skin should be patted gently with soft towel and emollient applied
- Patient should wear loose soft cotton clothing
- Nails should be kept short and the patient should rub the skin gently instead of scratching

PHARMACOLOGICAL MEASURES

Topical agents

Menthol 1-2% - substitutes itch with preferred sensation of cooling

Lidocaine 2.5% cream – for localized areas of itch

It should not be used for large areas as absorption through the skin can cause toxicity

Corticosteroids – useful when localized inflammation is present

Capsaicin 0.025% -.It depletes the neuropeptide substance P and is useful for localized itch

Oral Drugs

Anti-inflammatory agents-

- Corticosteroids- improve the symptom of itching in many patients but should be used for limited time because of adverse effects
- Antihistamines- for allergy e.g. cetrizine, fenofexadine
- Immunomodulation- thlidomide

Antidepressants- sertraline, paroxetine, mirtazapine -

5HT3 antagonists- ondansetron

Anticonvulsants- gabapentin, pregabalin
Bile acid sequestrants - useful in cholestasis- cholestyramine
Opioid antagonists- naloxone, naltrexone

REFERENCES

1. Pittelkow, M.R., Loprinzi, C.L., Pittelkow, T.P. (2015) Pruritis and sweating.In Hanks G et al (eds). Oxford Textbook of Palliative Medicine 5th ed. Oxford. OUP. Pp724-739
2. Symptom control – pruritis.www.palliativecareguidelines.scot.nhs.uk (24 December 2020)
3. Others- pruritis. www.guidelines.palcareindia.com (24 December 2020)
4. Twycross R, Wilcock A. Symptom management: other. Introducing palliative care. 5th Ed. Calicut. palliativedrugs.com. pp 211-32
5. Seccareccia D, Gebara N. Pruritus in palliative care: Getting up to scratch. Can Fam Physician. 2011;57(9):1010-e319.

B. SWEATING (hyperhidrosis)

Introduction

Sweating is a normal function of the body which allows it to maintain normal physiologic temperature (370F) in a hot environment.

Excessive or inappropriate sweating occurs in cancer patients as part of the disease or its treatment and it often occurs at night (nocturnal diaphoresis). It may be localized or generalized and causes emotional distress and social embarrassment.

The causes of excessive sweating are:

LOCALISED

- Neurogenic – spinal cord disease, peripheral neuropathy, cerebrovascular disease (stroke)
- Intrathoracic neoplasms or masses
- Unilateral circumscribed hyperhydrosis
- Associated with cutaneous lesions
- Cold-induced

GENERALIZED

- Infections – acute or chronic (tuberculosis)
- Malignancies – lymphomas, breast cancer, prostate cancer, neuroendocrine tumours, renal cell cancer, carcinoid syndrome, liver metastasis
- Hormonal deficiencies – menopausal or post-castration
- Endocrine – hyperthyroidism, hyperpituitarism, hypoglycaemia, diabetes mellitus
- Medications – opioids, SSRIs, hormone therapies (tamoxifen, aromatase inhibitors, gonadorelin analogues) tricyclic antidepressants (paradoxical), acyclovir
- Autonomic neuropathy
- Paraneoplastic sweating
- Emotional – anxiety, fear, stress

Assessment

- Detailed history- sweating generalized/localized, during day and/or night, severity, aggravating factors
- Medication review- any new medications
- Symptom assessment and physical examination
- Try to identify cause

Management

Correct the correctable

- Treat the underlying cause like an infection, if appropriate
- Drug induced – change medication and prescribe alternative e.g. Consider switching opioids, change antidepressant

Non-pharmacological measures

- Reduce room temperature – open windows, use fans or air conditioner
- Wear loose cotton clothing and use cotton bedsheets
- Avoid alcohol, hot drinks, hot and/or spicy food
- Frequent showering or sponge patient with a cool cloth
- Adequate fluid intake

Pharmacological measures

Sweating with fever

- Paracetamol 500 – 1000mg PO qid or prn
- Non-steroidal anti-inflammatory drug (NSAID) - Naproxen 250-500mg bid/prn PO or Ibuprofen 200 – 400mg PO tid or prn

Sweating without fever (associated with malignancy)
- Non-steroidal anti-inflammatory drug (NSAID)- Naproxen 250-500mg bid PO or Diclofenac 50mg tid PO
- Antimuscarinics – Glycopyrrolate 1-2mg tid
- H2 Antagonists - For both idiopathic and malignancy associated sweating-Tab Cimetidine 400-800mg od PO. Newer H2 Antagonists have not been tried
- Venalfaxine is used for hot flushes in premenopausal breast cancer patients. Starting dose 37.5mg od increased to 75mg od

REFERENCES

1. Pittelkow, M.R., Loprinzi, C.L., Pittelkow, T.P. (2015) Pruritis and sweating.In Hanks G et al (eds). Oxford Textbook of Palliative Medicine 5th ed. Oxford. OUP. Pp724-739.
2. Symptom control – sweating.www.palliativecareguidelines.scot.nhs.uk (24 December 2020).
3. Others- sweating. www.guidelines.palcareindia.com (24 December 2020).

C. DELIRIUM

Introduction

Delirium is a common neuropsychiatric syndrome found in advanced disease and is characterized by an acute onset of change in attention or awareness accompanied by a change in cognition.

Its incidence varies from 20-88% in palliative care patients, increasing in last weeks and days of life.

Based on clinical presentation delirium may be divided into three types hyperactive, hypoactive and mixed.

Causes

- Uncontrolled symptoms- Pain, constipation and urinary retention
- Metabolic/electrolyte disturbances- Hypercalcemia, hypoglycemia, hyponatraemia, dehydration
- Medications- Opioids, corticosteroids, benzodiazepines, alcohol withdrawal, nicotine

- Medication or substance withdrawal- opioids, benzodiazepines, alcohol, nicotine
- Infections- UTI, sepsis, pneumonia
- Renal and hepatic failure, hypoxia, anaemia
- Neurological- CVA, primary and metastatic brain cancer

Assessment

Delirium is very distressing for patients and family caregivers. If diagnosed early it may be reversed in 30-50% patients. Diagnosis is clinical and there should be a high index of suspicion in patients with advanced disease.

Detailed and accurate history should be taken from caregivers

Symptoms and signs

- Acute onset
- Fluctuating course
- Inattention
- Impaired memory
- Reversal of sleep-wake cycle
- Visual or auditory hallucinations
- Disorientation in time, place or person

Use a screening tool to diagnose- Nursing Delirium Screening Scale (NuDESC), Confusion Assessment Method (CAM)
Try to determine a cause- rule out urinary retention, constipation, uncontrolled pain
Review medications- look for opioid toxicity (drowsiness, myoclonus)
Differentiate from depression and dementia

Investigations

To be done depending on wishes of patient and family and stage of patient's illness
Complete blood count and biochemistry.
Check for urine infection in the elderly.

Management

Treat reversible causes-e.g. hyponatremia, infection
Maintain hydration
For opioid toxicity- decrease opioid dose or opioid rotation
Treat pain, constipation, urinary retention

Non-pharmacological management

- Explain cause and likely course to patients, caregivers, relatives
- Address patient's anxiety as patients with delirium are often frightened.
- Explain the symptoms to the family, teach them avoid confrontation with the patient and to answer all queries with patience and tact.
- The patient's room should be quiet, well lit, have familiar objects, with clock and calendar for orientation. If being used, glasses and hearing aids should be accessible.
- A soft light should be on during the night to avoid confusion and anxiety if the patient wakes up.
- The family caregivers should frequently re-orient the patient and involve him/her in daily activities
- Exposure to daylight during the day. Discourage sleeping during the day.
- Encourage patient to drink fluids
- No physical restraints
- Management of polypharmacy

Pharmacological management

It should be prescribed only if essential to control of symptoms.
Drug of first choice- Haloperidol
Starting dose- 0.5-1.5mg PO or SC stat and repeat after 2 hours if required.
Maintenance dose required if delirium cannot be reversed- 0.5-1.5mg od or bid PO SC
In elderly or frail patients start with a lower dose 0.25-0.5mg PO
For a patient who is hyperactive or agitated may add a benzodiazepine prn- Lorazepam 0.5-1mg PO or sublingually or SC
Quetiapine may be used in elderly patients as extrapyramidal side effects are less
Dose- 25 stat bid PO- In elderly start with 12.5mg stat and bid

Experience in managing delirium in homecare setting in India

Delirium is very common in the last 1-2 months of life. Using a screening tool helps to diagnose it early and in our setting we use NuDESC as it is very simple and easy to use in the field.

If delirium is due to causes like infection or hyponatremia, these may be treated and the delirium reversed.

When delirium is diagnosed early non-pharmacological measures may be enough to control symptoms or a low dose of haloperidol 0.5-1mg hs PO may be added.

Lorazepam 05-1mg is added if the patient is very hyperactive or agitated. In elderly patients, especially those ≥80yrs, an even lower dose of haloperidol, 0.25-0.5mg hs, is enough to control symptoms.

In the last days of life when swallowing is difficult, haloperidol is given SC to control delirium symptoms.

REFERENCES

1. Symptom control – delirium. www.palliativecareguidelines.scot.nhs.uk (27 December 2020).
2. Bush SH, Lawlor PG, Ryan K e al. Delirium in adult cancer patients: ESMO clinical practice guidelines. Annals of Oncol.2018; 29(4):iv143-iv165.
3. El Majzoub I, Abunafeesa H, Cheaito R, Cheaito MA, Elsayem AF. Management of altered mental status and delirium in cancer patients. Ann Palliat Med.2019;8(5):728-739.
4. Edelstein A, Alici Y. Diagnosing and Managing Delirium in Cancer Patients. Oncology. 2017; 31(9):686-692.
5. Leonard MM, Nekolaichuk C, Meagher DJ, Gaudreau JD, Watanabe S, Agar M. Practical assessment of delirium in palliative care. J Pain Symptom Manage.2014; 48(2):176-90.

Oncological Emergencies in Palliative Care

Oncological emergencies in palliative care are those conditions in advanced cancer patients that if left untreated would seriously threaten the quality of their remaining life. Before treating an emergency the following needs to be considered:

- The patient's condition and prognosis
- Patient's and family's wishes
- Whether treating the emergency will improve the patient's quality of life or will the proposed treatment cause more distress to the patient

Some emergencies can be anticipated in patients at risk and planned for. The situation can be discussed with the patient and family and the patient's wishes can be determined in advance and carried out.

A. MALIGNANT SPINAL CORD COMPRESSION

Introduction

Most cases of malignant spinal cord compression (MSCC) are caused by a vertebral body metastasis invading the epidural space posteriorly and compressing the spinal cord or caudaequina. A paraspinal lesion can also invade the epidural space through the intervertebral foramina. The compression causes irreversible neurological damage leading to paraplegia or quadriplegia depending on the level of the lesion.
Upto 5% of cancer patients develop MSCC and it is most commonly seen in multiple myeloma and cancers of the prostate, lung and breast. The most common sites of compression are thoracic (70%), lumbosacral (20%) and cervical (10%).

Assessment

MSCC can occur in any cancer patient but they should be anticipated in patients at risk of bone metastases or in those who already have bone metastases.

Signs and symptoms

Progressively severe back pain, band like pain encircling abdomen or chest.
Motor deficits: Difficulty in walking- decreased muscle power.
Sensory deficit: Paraesthesias and numbness in feet ascending to legs.
In late stages there is loss of bladder/ bowel sphincter control leading urinary retention and constipation or fecal incontinence.

Management

Patients at risk and their caregivers should be educated on the symptoms that may occur like severe back pain and weakness in limbs as prompt treatment is essential to preserve neurological function. If treatment is initiated within 24-48 hrs of symptom onset neurological damage may be reversed.

Management depends on patient's disease stage, prognosis, performance status and patient's and family's wishes.

Immediate treatment

-Dexamethasone 16mg bolus dose given IV or PO immediately

Further treatment

This depends on the patient's extent of disease, prognosis and performance status and goals of care of the patient and family.

- Patients with a good performance status should be referred immediately to an oncology centre for further management, usually radiotherapy after MRI spine.
- Patients who are bedridden and or those with multiple metastases and poor prognosis may be continued on dexamethasone 16mg for 3-5 days and then reducing the dose gradually over 2-3 weeks
- Return of neurological function depends on patient's mobility at start of treatment. About70% who can walk before treatment maintain mobility, 35% of those with weakness regain function and only 5% of those are completely paraplegic do so. For this reason early diagnosis and treatment is essential.

Managing SCC in the homecare setting in India

Most patients are diagnosed because of symptoms like severe back pain and difficulty in walking due to decreased muscle power in lower limbs. Due to the advanced stage of their disease majority of patients are unwilling to go to hospital and are started on dexamethasone 16mg SC/PO od x 1-3days and then the dose is reduced gradually over 2-3 weeks. If dexamethasone is started while patients are mobile to some extent then some mobility is retained and may also improve a little. However if the patient is already paraplegic dexamethasone will not help to bring mobility back.

REFERENCES

1. Falk S, Reid C. Emergencies. In Fallon M, Hanks G (eds) ABC of Palliative Care 2nd ed. Oxford. Blackwell Publishing. pp. 40-43.
2. Caraceni, A., Martini, C., Simonetti, F. (2015). Neurological problems in Advanced Cancer.In Hanks G et al (eds). Oxford Textbook of Palliative Medicine 5th ed. 2015. Oxford. OUP.pp 686-701.

B.SUPERIOR VENA CAVA OBSTRUCTION

Introduction

Superior vena cava obstruction (SVCO) can occur due to external compression by a tumor or node, intraluminal thrombus formation or direct invasion of vessel wall by cancer. Most cases are due to a mediastinal tumor of which 75% are caused by bronchial carcinoma and 15% are due to lymphomas.

Assessment

SVCO is often a clinical diagnosis

Symptoms

Breathlessness
Swelling of face, neck and arms
Cough, hoarseness of voice
Headache
Dysphagia

Signs:

Tachypnoea
Dilated neck and chest veins
Facial, periorbital, neck and arm oedema
Congested conjunctivae, facial plethora
Cyanosis
Vocal cord paralysis
Horner's syndrome

Management of SVCO

SVCO may be the initial presentation of a suspected malignancy and the management will depend on the histological diagnosis.

Symptom management in advanced cancer patients:

- Patient nursed in propped up position
- High dose steroids can be started- dexamethasone 16mg PO or SC, then continue 16mg PO od or bid dose for 5-7 days. Stop if no relief in 5 days
- Loop diuretics- Furesomide 40-80mg/day PO ortorsemide 5-10mg/day PO
- Opioids for breathlessness – 2.5-5mg q6h (see guidelines on breathlessness)
- Oxygen for hypoxaemia
- Clothing may be loosened and arms supported on pillows

Further management depends on the stage of patient's disease, prognosis, performance status and patient's and family's wishes.

All decisions are to be made after discussion of patient's condition and prognosis with the family and/or patient.

Patients, if their condition permits, may be referred to an oncology centre for further investigations and management- stenting or radiotherapy and/or chemotherapy as decided by oncology centre team

Patients with poor performance status and/or in the last days of life are given symptom management.

REFERENCES

1. Falk S, Reid C. Emergencies. In Fallon M, Hanks G (eds) ABC of Palliative Care 2nd ed. 2006. Oxford. Blackwell Publishing. pp. 40-43.
2. Hoskin PJ. Radiotherapy in symptom management. In Hanks G et al (eds). Oxford Textbook of Palliative Medicine 5th ed. 2015. Oxford. OUP.pp 771-89.
3. Twycross R, WilcockA.Emergencies.Introducing palliative care. 5th Ed. Calicut. palliativedrugs.com. pp 233-57.
4. Palliative emergencies – Superior vena cava obstruction. www.palliativecareguidelines.scot.nhs.uk (11 December 2020).
5. Talapatra K, Panda S, Goyle S, Bhadra K, Mistry R. Superior vena cava syndrome:A radiation oncologist's perspective. J Can Res Ther. 2016; 12:515-9.
6. Lepper PM, Ott SR, Hoppe H, et al. Superior vena cava syndrome in thoracic malignancies.RespirCare. 2011;56:653–66.

C. HYPERCALCEMIA

Hypercalcemia is the most common life-threatening metabolic disorder in cancer patients. It is defined as serum calcium more than 10.5mg/dL or 2.66mmol/L. (Normal calcium is 8.5 to 10.5mg/dL).
It occurs most commonly in patients with multiple myeloma, breast cancer and lung cancer.

Symptoms and signs

Confusion, lethargy, obtundation
Nausea, vomiting, constipation
Polyuria and polydipsia
Dehydration

Investigations

Blood urea, serum electrolytes, albumin and calcium
Corrected Calcium Formula-
Corrected calcium (mg/dL) = measured total Ca (mg/dL) + 0.8 (4.0 - serum albumin [g/dL]), where 4.0 represents the average albumin level.

Management

Treatment depends on goals of care. Refer the patient to hospital if treatment of hypercalcemia is appropriate.

In patients with a good performance status prior to present episode and if patient and family are willing for blood tests and intravenous treatment then refer to hospital.
In patients with advanced disease who have a recurrent episode of hypercalcemia within a short period of time (e.g. within 10-14 days) prognosis is usually poor and depending on patient's and family's wishes may be managed symptomatically at home.

When the patient is in the last days of life the goals of care change and the patient may be managed symptomatically at home.

Management of Hypercalcemia

- Corrected calcium value is used for decisions about treatment
- Stop drugs which may contribute to/worsen hypercalcemia (thiazide diuretics, calcium supplements, calcitriol)

- Rehydrate with 2-3L fluids (0.9% saline). Amount and rate depend on clinical and cardiovascular status and concentrations of urea and electrolytes
- After a minimum of 2 L of intravenous fluids give bisphosphonate infusion - Zoledronic acid 4 mg in 100ml normal saline over 15 minutes
- The dose of bisphosphonates needs to be adjusted for decreased renal function
- Bisphosphonates may produce flu-like symptoms
- Measure urea and electrolytes concentrations daily and give intravenous fluids as necessary
- Normalisation of serum calcium takes 3–5 days. Do not measure serum calcium for at least 48 hours after rehydration as it may rise transiently immediately after treatment

To prevent recurrence of hypercalcemia

Treatment of underlying malignancy, if appropriate
Bisphosphonates (Zoledronic acid) monthly - may be given at home
Monitor serum calcium levels monthly

REFERENCES

1. Falk S, Reid C. Emergencies. In Fallon M, Hanks G (eds) ABC of Palliative Care 2nd ed. Oxford. Blackwell Publishing. 2006 (pp 40-43).
2. Bower, M., Robinson, L., Cox, S. (2015). Endocrine and metabolic complications of advanced cancer. In Hanks G et al (eds). Oxford Textbook of Palliative Medicine 5th ed. 2015. Oxford. OUP.pp 906-18.

D. HAEMORRHAGE

Causes

10-20% of patients with advanced cancer have some form of bleeding and it is a very distressing symptom for them as well as their caregivers. In about 5% patients it could present as a terminal event.

CAUSES IN CANCER PATIENTS

- Cancer invasion and destruction- head and neck, lung, rectal and gynaecological malignancies, acute myeloid leukemia
- Treatment-related - Chemotherapy with cyclophosphamide, ifosfamide can cause chemical cystitis and bleeding (as a late complication). High dose radiotherapy can cause

mucositis in the gastrointestinal tract
- Thrombocytopenia/marrow failure
- Drugs – NSAIDS, dexamethasone. Excessive anticoagulant therapy, either overdosing or drug interactions in cancer patients on anticoagulant treatment
- Coagulation disturbances- due to disseminated intravascular coagulation, secondary fibrinolysis, primary fibrinolysis and drugs and liver disease

Assessment

History of bleeding from patient and family:
- **Consider site of bleeding-** hemetemesis, haematochezia, haemoptysis, epistaxis, vaginal bleeding, ulcerated surface wound, ecchymoses, petechiae or bruising, multiple sites in systemic causes, insidious bleeding in malaena.
- **Duration and volume** - Bleeding could be a one-time event, recur intermittently or continuous. Small intermittent bleeds could herald large bleeds. Large ulcerating chest lesions from advanced breast cancer may present as continuous low grade oozing from the underlying vascular bed going up to several ml/day.Rarely, haemorrhage can be massive and catastrophic causing hypovolemia and death in minutes.
- Check pulse, BP.

Investigations (if appropriate according to goals of care)

Complete blood count, liver function tests, coagulation profile (including INR)
Patients at high risk of bleeding should be identified and preventive steps taken before a crisis occurs. Patients at increased risk are:
- Severe thrombocytopenia - <20000
- Large head and neck cancer wounds
- Large centrally located lung cancer
- Severe liver disease
- Refractory acute and chronic leukemias
- Patients with advanced cancer on anticoagulants

Management

ANTICIPATORY PLANNING

Caregivers of patients at risk for major bleeds should be informed and prepared for such an event.
The caregivers should have the contact number of the team doctor and nurse to contact in an emergency.

An anticipatory care plan should be discussed with the caregivers–application of pressure to the bleeding site using dark towels, comfort and care of patient, options for sedation and whether the caregiver will be able to administer the medication
The futility of resuscitation should also be discussed with the caregivers.

MANAGEMENT OF ACUTE SEVERE HAEMORRHAGE

The caregiver should try to remain calm and call the given emergency number.
Direct pressure should be applied to the bleeding site using dark towels
The patient may be referred to hospital depending on patient's/caregiver's wishes and what has been discussed with them.

Massive or Terminal Haemorrhage: If patient has a massive haemorrhage and is dying the caregiver should remain with the patient for comfort and support. Dark towels and sheets should be used to decrease the visual impact. Sedative medication may be given to the patient if it is at the patient's bedside. The caregiver should not leave the patient to get it as it is more important that they remain with the patient.

MANAGEMENT OF MINOR BLEEDING

-Direct pressure on wound where anatomically possible
-Review drugs and discontinue/decrease dose of drugs known to increase bleeding-aspirin and NSAIDs anticoagulants may be discontinued or withheld temporarily till bleeding subsides.

MANAGEMENT OF BLEEDING FROM SPECIFIC SITES

Bleeding from skin and malignant wounds

- Direct pressure should be applied where possible with gauze/clean cotton cloth pad/ towel.
- A paste of tranexamic acid tablets (4x500mg) may be applied to the wound. Gauze/cloth pad may be soaked in inj tranexamic acid (500mg in 5ml) and applied with pressure on the wound. Dressing may be done over the soaked gauze.
- Non-adherent dressing like paraffin gauze or liquid paraffin soaked gauze may be used.
- Heamostatic dressings like Kaltostat dressing may be used depending on availability and cost.
- Tranexamic acid 500-1500mg tid PO

BLEEDING FROM ORAL MUCOSA

Oral rinse with 5% tranexamic acid solution (500mg/10ml)- swish in mouth and then swallow tid

EPISTAXIS

- Nostril may be packed with gauze soaked in tranexamic acid solution (inj tranexamic acid 500mg/5ml)
- Tranexamic acid 500-1500mg tid PO

HAEMOPTYSIS

- Maintain airway
- Place the patient in a head down position to aid drainage of blood
- Tranexamic acid 500-1500mg tid PO

UPPER GI BLEEDING

- Proton pump inhibitor or H2 antagonist
- Sucralfate 2g bid PO
- Tranexamic acid 500-1500mg tid PO
- Octreotide – 300mcg/24hr SC

RECTAL BLEEDING

- Sucralfate enema 20ml of 10% solution bid (2g/20ml)
- Tranexamic acid 500-1500mg tid PO
- Ethamsylate 500mg q8h/q6h PO

HAEMATURIA

In patients where hematuria can be expected as in a bladder tumor discuss this with the patient and/or family

Haematuria caused by UTI may be treated with antibiotics

For mild hematuria encourage the patient to increase fluid intake

For moderate to severe hematuria bladder irrigation with cold normal saline is done

VAGINAL BLEEDING

Pack soaked in tranexamic acid or sucralfate

REFERENCES

1. Eric Prommer. Management of bleeding in the terminally ill patient, Hematology. 2005; 10(3): 167-175.
2. Ubogagu E, Harris DG. Guideline for the management of terminal haemorrhage in palliative care patients with advanced cancer discharged home for end-of-life care. BMJ Support Palliat Care. 2012 Dec 1;2(4):294-300.

E. SEIZURES

Introduction

Seizures occur in 10 to 15% of palliative care patients and may be generalized or partial.

Causes

CNS- primary or secondary brain tumours, cerebrovascular disease, epilepsy
70% of patients with brain tumours have seizures during the course of their illness.
Biochemical abnormalities-hypoglycemia, hyponatremia, hypercalcaemia or uraemia.
Drugs -antidepressants, antipsychotics (haloperidol) and tramadol
Withdrawal of alcohol and benzodiazepines
Chemotherapy agents - paclitaxel and ifosfamide

Assessment

- Full history and examination to be taken after a seizure
- Previous history of epilepsy, previous secondary seizures and cause e.g. cerebral disease
- Determine the cause of the seizures or loss of consciousness. Eliminate other causes of loss of consciousness e.g. postural hypotension, vasovagal episode, hypoglycemia, arrhythmia
- Blood investigations and neuro-imaging may be required to determine cause
- Details of medications patient may be taking for seizures and adherence to advised dose.

Management

- Prophylactic anticonvulsant therapy in brain tumors is not recommended. Long term anticonvulsant therapy should only be started after the first episode of seizures.
- Reversible causes of seizures should be treated and anticonvulsants are not required
- Patients with irreversible causes of seizures should be started on anticonvulsants.
- Classic antiepileptic drugs like phenytoin should not be prescribed to patients with brain tumors who are receiving radiotherapy, chemotherapy or corticosteroids due to idiosyncratic adverse effects and interactions.

- Monotherapy should be should be used to control seizures and dose of drug should be gradually titrated till seizures are controlled. If seizures are not controlled with monotherapy a second drug may be added or a neurologist consulted.

ACUTE SEIZURE MANAGEMENT

Education of family members

- Do not try to restrain the patient.
- Do not put anything in the patient's mouth e.g. spoon, gauze piece.
- When the seizure ends put the patient onto his/her side.
- The patient will be drowsy for some time after the seizure.
- Most seizures are self-limiting and terminate within 5minutes so acute anticonvulsant administration is not required during or after every seizure.
- Acute antiepileptic treatment is required when a generalized seizure lasts for more than 5minutes or two or more seizures occur in quick succession without the patient recovering consciousness in between and in this situation the family caregiver should seek medical help.

ACUTE MANAGEMENT OF SEIZURE SAND STATUS EPILEPTICUS

Check airway, safe positioning

-Inj Lorazepam 4mg -2mg/min IV or SC and repeat once after 10-20 minutes(maximumdose8mg)

SC route used in homecare setting when IV route not available

OR

If IV access available - Inj Diazepam 10mg IV – repeat every 5 minutes till seizures controlled

Maximum dose – 40mg- diazepam should not be given SC

If seizures continue:

Inj Midazolam 5-10mg IV or SC – Repeat every 15 minutes upto 3 times

If seizures persist

CSCI Midazolam 30-100mg/24hrs (0.1-0.6mg/kg/hr)

Patients having repeated episodes of prolonged seizures should be advised rectal diazepam (suppositories) and the caregiver should be taught how to administer these. Rectal suppositories (5mg/suppository) dose- 10mg (2 suppositories) administered PR every 5-10 minutes till seizures controlled to a maximum dose of 40mg.

REFERENCES

1. Guidelines for the management of seizures. www.palliativedrugs.con (internet) 2015 (23 December 2020).
2. Palliative emergencies-seizures. www.palliativecareguidelines.scot.nhs.uk (23 December 2020).
3. Palliative emergencies- seizures. www.guidelines.palcareindia.com (23 December 2020).
4. León Ruiz M, Rodríguez Sarasa ML, Sanjuán Rodríguez L, Pérez Nieves MT, Ibáñez Estéllez F, ArceArce S, García-AlbeaRistol E, Benito-León J. Guidelines for seizure management in palliative care: Proposal for an updated clinical practice model based on a systematic literature review. Neurologia. 2019 Apr;34(3):165-197.
5. Practical Management of Epileptic Seizures and Status Epilepticus in Adult Palliative Care Patients. Gronheit W, Popkirov S, Wehner T, Schlegel U, Wellmer J. Front Neurol.2018 Aug 2;9:595.
6. A., Martini, C., Simonetti, F. (2015). Neurological problems in Advanced Cancer.In Hanks G et al (eds). Oxford Textbook of Palliative Medicine 5th ed. Oxford. OUP.p 686-701.
7. Twycross, R., Wilcock, A., Howard, P. (2014). Central Nervous System – Anti-epileptics. Palliative Care Formulary 5. (pp. 342-384).
8. Tradounsky G. Seizures in palliative care. Can Fam Physician. 2013;59(9):951-e405.

NURSING ISSUES IN PALLIATIVE CARE

A. LYMPHOEDEMA

Lymphoedema is a condition of localized fluid retention and swelling caused by a compromised lymphatic system. It usually affects the limbs but can involve any part of the body. It is an incurable condition and it can be alleviated by appropriate management.

Causes

PRIMARY

- Congenital
    a. Lymphoedema praecox
    b. Lymphoedema tarda

SECONDARY

- Advanced cancer- lymphatic obstruction due to direct invasion or nodal involvement
- Cancer Treatment – radiotherapy and surgery
- Infection – post cellulitis
- Trauma
- Secondary to chronic venous disease
- Chronic skin disorders
- Filariasis
- Obesity

Cancer (the disease or its treatment) is the main cause of lymphoedema in palliative care patients.

Stages of Lymphoedema

Based on severity lymphoedema is divided into the following stages:

- **Stage 0** (Latent stage)

    There are no visible changes in affected area (arm, hand, or upper body) but the patient may notice a difference in feeling, such as a mild tingling, unusual tiredness, or slight heaviness. This stage can be present for months or years before obvious symptoms develop.

- **Stage 1** (Mild)

  There is mild swelling of the affected area. Pitting oedema is present. Swelling at this stage is soft, and may respond to elevation. This early-stage lymphoedema is considered reversible with treatment because the skin and tissues haven't been permanently damaged.

- **Stage 2** (Moderate)

  There is increased swelling of the affected area (pitting oedema) and it does not decrease with elevation. Skin and tissue thickening/hardening has occurred with the increase in limb volume. Stage 2 lymphedema can be managed with treatment, but tissue damage can't be reversed.

- **Stage 3** (Severe)

  This is the most advanced stage and the affected limb or area of the body becomes very large and misshapen. The skin takes on a leathery, wrinkled appearance and skin changes are observed- fibrosis, hyperkeratosis, hyperpigmentation, papillomatosis.

Assessment

HISTORY AND EXAMINATION

- Onset and duration
- Distribution and extent of swelling, presence of pitting

  In unilateral lower limb swelling of recent onset it is important to exclude deep vein thrombosis.
- Pain- often described as an ache, tightness or heaviness
- Impaired mobility/use of limb – due to increased weight of the limb or due to stiffness caused by firm swelling around the joints. This is more problematic in lower limb lymphoedema.
- Skin changes- these are observed in stage 2 or 3 lymphoedema
  a. Skin thickening
  b. Hyperkeratosis
  c. Papillomatosis
  d. Increased skin creases especially around joints
  e. Stemmer's sign is positive - this is the inability to pick up a fold of skin over the proximal phalanx of second toe in lymphoedemaof the leg due to the skin and subcutaneous tissue changes.

- Presence of cellulitis or lymphorrhoea

  Circumferential measurement of both affected and unaffected limbs with a tape- a finding of >2cm difference between the two limbs is significant.
- Lymphoedema stage should be determined as this helps in planning management

Psychosocial assessment

Patients may experience significant distress because of their lymphoedema:

- Altered body image
- Decreasing functional ability and loss of independence
- Loss of job and income
- Feeling of hopelessness
- Social isolation.

Lymphoedema Prevention

Patients at risk should be educated about lymphoedema and precautions to be taken in order to prevent occurrence:

- Keep limb clean, dry, supple and moist
- Infection prevention in 'at risk' limb
  a. Avoid injections, blood pressure measurement, blood samples
  b. Avoid cuts, scratches, or bites
  c. Care while removing body hair
- Avoid tight clothing, jewelry, shoes
- Regular exercises
- Compression garment during air travel
- Maintaining optimal body weight as excess weight is associated with decreased lymphatic function

Patients should also be educated about early signs of lymphoedema and who to contact if swelling occurs.

Management

Management is long-term and the goals of care are:

- Patient self-management
- Maintain function
- Improve comfort and quality of life
- Reduce limb volume/restore natural shape
- Improve condition of skin and soft tissues

- Prevent complications

Lymphoedema is managed by a combination of physical techniques known as decongestive lymphoedema therapy and comprises the following:

- Skin care
- Lymphatic Massage
- Compression
- Exercise

SKIN CARE

The aim of skin care is to decrease the risk of infection (see lymphoedema prevention above).

Patient is advised the following:

- Wash skin daily with a mild soap, dry thoroughly paying special attention to area between digits and any skin folds and apply emollients (coconut oil)
- Where skin is dry and flaky or rough and scaly emollients may be applied 2-3 times a day
- Observe normal and affected skin for cuts, abrasions and insect bites with special attention to any area affected by sensory neuropathy
- In the affected limb avoid:
    a. injections/venepuncture
    b. waxing or razors
    c. blood pressure cuffs
    d. glass bangles
- In upper limb lymphoedema wear gloves or mittens while working in the kitchen or garden
- In lower limb lymphoedema wear footwear to avoid injuries

LYMPHATIC MASSAGE

Lymphatic massage which may be manual lymphatic drainage (MLD) or simple lymphatic drainage (SLD) aims to reduce swelling by encouraging lymph flow.
MLD is a gentle massage technique which encourages lymph flow away from congested areas by increasing activity of normal lymphatics and bypassing those that are damaged or obliterated.

To be effective MLD should be combined with other techniques especially compression
MLD is performed by a trained professional preferably daily.
It is performed with the patient in the supine position and starts with deep diaphragmatic breathing.

It treats the unaffected lymph nodes and areas of the body first, moving from proximally to distally to drain affected areas.

The movements are slow and gentle pressure is applied. Deep pressure will stimulate blood flow and worsen oedema.

SLD is similar to MLD and motivated patients/caregivers should be taught how to do it. It should be done for 15-20 minutes daily and a regular check should be done to ensure it is being done correctly.
Compression
Compression technique may be applied through:
Multi-layer lymphoedema bandaging
Compression garments
Intermittent pneumatic compression pump

MULTI-LAYER LYMPHOEDEMA BANDAGING (MLLB)
MLLB comprises a series of layers of inelastic or low stretch bandages applied to a swollen limb, which creates a graduated compression with the pressure reducing from the distal to proximal part of the limb. A massaging effect is produced which stimulates lymphatic flow.
The bandages need to be applied by a trained professional
Indications:
Initial management of stage 3 lymphoedema (distorted limb shape with skin changes)
Limb too large for compression garments
In advanced cancer with lymphorrhoea a modified bandage (fewer layers and less pressure) can help control symptoms of heaviness and leakage

COMPRESSION GARMENTS
These are graduated elastic compression garments which are used for long-term management of lymphoedema. They may be ready to wear or made to order
Ready to wear compression garments are suitable for patient with minimal or mild swelling (stage 1) while patients with moderate or severe lymphoedema or those who are obese will probably require made to order garments.

INDICATIONS
– Used following a period of intensive therapy with MLLD in stage 3 lymphoedema.

– As initial therapy for mild and/or moderate lymphoedema

Contraindicated in patients with damaged skin, exaggerated skin fold or lymphorrhoea

WEARING AND CARING OF COMPRESSION GARMENTS

- The patient should have 2 garments, one to wear and one to wash
- After wearing the garment all folds and wrinkles should be smoothened out
- The top end of the garment should not be folded down
- Emollients can damage the garment so it should be applied about an hour before wearing the garment or a cotton liner may be used if emollient is used just before the garment is worn.
- A cotton liner may also be worn if there is any rash or dermatitis to prevent skin damage
- If there is any skin redness/damage/discoloration or peripheral swelling the garment should be removed immediately. The cause should be determined and corrected e.g. an ill-fitting garment may need to be changed
- The garment should be washed by hand with soap and water (or according to manufacturer's guidelines. It may be washed daily (in a hot humid climate) or on alternate days
- The garment should be changed when it is deformed or damaged. A review may be done after about 6 months

EXERCISE/MOVEMENT

All types of exercise are known to improve lymph and venous flow.

-Exercises should advised according to patient's needs, ability and disease status

-Patient should be encouraged to maintain normal routine activity and movement

-A combination of flexibility, resistance and aerobic exercises should be advised

-Start with low to moderate intensity exercises- simple range of motion exercises

-If possible, simple aerobic exercises like walking should be encouraged.

PHARMACOLOGICAL MANAGEMENT

There is little role for drugs in management of lymphoedema

Complications of Lymphoedema and Management

CELLULITIS

Patients with lymphoedema are more prone to developing cellulitis in affected limb

Diagnosis- history of fever and malaise with pain, redness and swelling in affected limb

Management- Antibiotics, NSAIDs, rest

Compression garment use, MLD/SLD and exercises should be discontinued during acute episode.

LYMPHORRHOEA

Lymphorrhoeais the leakage of lymph from an oedematous limb through defects in the skin.

Profuse leakage is very distressing for the patient. Patients at the end-of-life sometimes develop severe oedema of the lower limbs. Homecare nurses should be alert to development of lymphorrhoea in these patients and should also educate caregivers about this so that it may be detected early.

Management- Compression bandaging (fewer layers and less pressure than MLLB)

The site of leakage should be covered with a non-adherent absorbent dressing

The bandaging may initially have to be changed a number of times/day, especially if there is profuse lymphorrhoea, to avoid maceration of skin.

The leaking may decrease and stop in 2-4 days and the bandaging may be discontinued once it stops completely. Sometimes the leakage is persistent and bandaging needs to be continued.

REFERENCES

1. Keeley V. Lymphoedema. In Hanks G et al (eds). Oxford Textbook of Palliative Medicine 5th ed. Oxford. OUP.pp 740-746.
2. Fu MR, Lasinki BB. Lymphoedema management. In Ferrell BR et al (eds). Oxford Textbook of Palliative Nursing 4th ed. Oxford, OUP. pp 279-296.
3. Lymphoedema Framework. Best practice for the management of lymphoedema: an international consensus. London, MEP. 2006.
4. Physio-pedia.com. Lymphoedema.[internet].https://www.physio-pedia.com/Lymphoedema (accessed 16 November 2021).

B. WOUND MANAGEMENT

Malignant Wounds

Malignant wounds occur when cancer cells from a primary or metastatic cancer invade the skin and its supporting blood vessels and lymphatics resulting in tissue necrosis resulting in an ulcerative wound or a fungating growth extending from the surface of the skin.

They occur in 5-19% of patients with metastatic disease and are most commonly associated with head and neck cancers, breast cancers, skin cancer and metastatic cancers to the skin and genital cancers.

Malignant wounds may heal in response to anti-cancer therapy but often do not. In advanced cancer patients they are mostly non-healing and management is palliative.

Common problems of malignant wounds are: discharge or exudate, malodor, bleeding, pain, maggots and infection. The aim is good pain and symptom management, addressing psychosocial issues, empowering independence and ADL thus maintaining patient's dignity and quality of life.

Assessment

HISTORY

- Detailed history of wound- onset, presence of pain, exudate, foul smell or bleeding
- Treatment history- how the wound is being managed and mediations patient is taking
- Impact of the wound on the patient- any problem in eating, drinking or sleeping or in ADL, psychosocial impact (body image, social isolation, feelings of guilt, shame, anger)

EXAMINATION

- Location, size and depth of wound, fungating or ulcerative
- Presence of foul smell, exudate, bleeding, maggots
- Presence of pain and its intensity

Management

MANAGEMENT OF WOUND

Explanation and education on care of wound and its importance to patient and caregiver so that either of them is able to change the dressing.

The dressing must be changed daily and the wound must be kept covered at all times to prevent maggots.

CLEANING AND DRESSING OF WOUND

- Gentle irrigation with normal saline or home-made saline (boiled cooled water with a pinch of salt)
- After the wound is cleaned, 2% metronidazole gel or metronidazole powder (prepared by crushing metronidazole tablets) is applied. This helps to control malodor
- Paraffin gauze tulle may then be applied to prevent the dressing from sticking
- Apply dressing pad for exudate
- Secure with bandage or tape

WOUND PAIN

- Pain assessment and prescription of analgesics (see guideline on pain management)
- Pain during dressing- give pain medication 30 minutes before procedure
- Soak adherent dressing with normal saline for 3-5 minutes before removal and/or use paraffin gauze dressing as a base layer
- Apply xylocaine jelly to the wound surface after removing old dressing

MALODOUR

Metronidazole, topical as well as systemic is very effective in managing malodour
2% metronidazole gel or metronidazole powder (prepared by crushing metronidazole tablets) applied to wound after cleaning. Gauze soaked in IV metronidazole solution can also be applied on the wound.
Tab Metronidazole 400mg tid PO x 7days is very effective in treating malodour when malodour is severe or poor response to topical metronidazole.
Honey dressings are also effective in decreasing malodour.
Charcoal pieces kept in the patient's room.
Incense sticks (agarbattis), room deodorisers and perfumes can be used to mask malodour if tolerated by patient.

EXUDATE

A secondary absorbent dressing pad may be placed over primary dressing to absorb exudate.
Honey dressing has been found to decrease excessive exudate and may be used.
Absorbent dressings such as alginates, foams and hydrofibres are also available.

INFECTION

Clean with saline

Topical antibiotic for superficial infection - 2% metronidazole gel or metronidazole powder
Oral antibiotics- for deeper tissue infection (surrounding oedema, excessive exudate, severe malodour)
Avoid excessive debridement, hydrogen peroxide (can harm healthy tissue) and betadine (can cause toxicity over long term use or when applied over a large area)

BLEEDING

If dressing is adherent soak with saline before removing
Apply local pressure/cold compress
Tranexamic acid- crushed tranexamic acid tablet
Oral Tranexamic 500mg -1.5gm tds
IV Tranexamic Acid 500mg
Ethamsylate 500mg tid/qid
In patients with repeated bleeding episodes or large or deep wounds possibility of erosion of major blood vessel causing terminal haemorrhage. Prepare family in advance (see guideline on terminal haemorrhage).
Honey Dressings are very effective in decreasing bleeding as well as malodour and exudate. Medicated honey is very expensive but any good quality commercially available honey may be used and is effective.
Honey dressing technique – Soak sterile gauze in honey and squeeze out excess honey. Apply the honey-soaked gauze on the wound, cover with dry gauze and dressing pad. Change dressing every day.

MAGGOTS

Turpentine oil- Put gauze soaked in turpentine oil on the wound and physically remove the maggots when they appear.
Repeat process daily till no more maggots
Tab Ivermectin 12mg od x 1-days- causes death of parasite and early decrease in maggot numbers

Management of psychosocial problems

It is important to also focus on and address the patient's understanding and knowledge of his disease and wound, the effect on body image, social stigma, relationship issues and feelings of guilt, shame, anger and/or fear of death.
The family should also be involved and this may improve their understanding and help to resolve issues of isolation and withdrawal.

Managing malignant wound in a homecare setting in India

Malignant wounds are most common in patients with advanced head & neck cancer and are also seen in some breast cancer patients. It is important to educate patients and caregivers on cleaning and dressing of wounds. Wounds with excessive discharge are well managed using honey dressing (commercially prepared honey used) and adding metronidazole to the dressing takes care of foul smells. Maggots in malignant wounds are common in patients living in slums or areas with poor sanitation. Turpentine oil on the wound, physical removal of the maggots and ivermectin given orally help to manage this problem. Ivermectin given once a month helps to decrease the incidence of recurrence of maggots in these patients.

REFERENCES

1. Rajagopal M.R., Nandini V., Mathews L., Rajashree K.C., Watson M. Symptom assessment and management: malignant wounds, Wound assessment-Management of malignant wounds. An Indian Primer of Palliative Care. Tiruvananthapuram.Pallium India 2017. (pp. 123-126).
2. Watson H, Hughes A. BC Cancer Agency Care and Resaerch. Symptom management guidelines: Care of malignant wounds. 2015. Available from: www.bccancer.bc.ca/nursingsite/Documents/10.%20Malignant%20Wounds.pdf. [Accessed December 29 2020].
3. Grocott P, Gethin G, Probst S. Skin problems in palliative care. In Hanks G et al (eds). Oxford Textbook of Palliative Medicine 5th ed. Oxford. OUP.pp 715-723.
4. O'Brien C. Malignant wounds: managing odour. Can Fam Physician. 2012;58(3):272-e143.

C. PRESSURE SORES

Pressure sores or ulcers are areas of localized injury to skin or underlying tissue usually over a bony prominence as a result of persistent pressure leading to impaired blood supply and tissue necrosis. The most common locations for pressure sores are the sacrum, greater trochanters, ischial tuberosities, heels and lateral malleoli. Bed bound patients are at great risk of developing pressure sores.

Risk factors for pressure sores

- **Immobility/limited mobility -** most important risk factor and common in palliative care patients
- **Sensory loss -** In spinal cord injuries and CVAs
- Moisture removes oils from skin making it more friable and can also cause tissue maceration
- **Incontinence** (urinary and fecal) - presence of moisture and bacteria from stool
- **Shear and friction** - these forces act on skin of bedridden patients damaging epidermis and dermis e.g. when they slip down the bed from a semi-sitting position
- **Poor nutrition -** hypoalbuminemia weight loss, cachexia and malnutrition
- **Age-related skin changes** in elderly
- **Co-morbidities and psychological factors -** altered mental state, advanced cancer, dementia, depression, and chronic emotional stress

Prevention of pressure sores

Risk factors should be identified and routine skin assessment done. Preventive measures should be used in at- risk patients.

Routine skin assessment - Caregivers should be educated about pressure sores and their prevention and advised about daily inspection of the patient's skin, especially over bony prominences, for early identification. Any skin changes like non-blanchable erthythema or colour changes should be informed to the homecare nurse. The homecare nurse should also inspect the skin of at-risk patients on every visit.

PREVENTIVE MEASURES

Regular turning

- Bed bound patients should be assisted in turning or turned every 2-3 hrs by caregivers.
- When a patient is placed in the side position pillows may be placed behind the back to provide support and/or maintain position.

Alternating pressure air mattress

- An air mattress reduces the incidence of bedsores and should be used for bedridden

patients in the homecare setting. The patient still needs to be turned but the frequency may be decreased to every 4-5 hours.
- In cachectic or thin-built patients an air mattress may cause significant pain on bony prominences. In such patients, especially at the end-of-life, regular turning every 2-3 hours may be a better option.

Pillow-bridging
- Pillows placed between the knees, between the heels and under the ankles prevent pressure sores from developing on the medial surface of knees, on the medial malleoli and on the heels.
- The pillow placed under the ankles should keep the heels off the surface of the bed.

Reducing shear and friction
- Care should be taken while moving the patient in bed so the skin is not dragged over the bed surface e.g. a draw sheet may be used to pull up or position a patient in bed.
- The bed sheet should be kept free of wrinkles.
- The head end of the bed should not be elevated more than 30 degrees.

Skin care
- Patient should be bathed or sponged daily using mild soap and water and skin should be dried thoroughly.
- Special care should be taken while cleaning and drying perineal area and skin folds.
- The skin should then be moisturized with moisturizing cream/lotion/coconut oil and this should be done twice a day.
- In incontinent patients regular diaper change is required and the area should be cleaned well and emollient applied after each change. For incontinence rash zinc oxide cream may be applied.
- Rubbing alcohol or powder should not be applied to the skin.

Nutrition

Nutrition can be a major risk factor for development of pressure sores in palliative care patients. Protein supplement should be encouraged in patients who can tolerate it. Increasing protein intake through artificial nutrition is not recommended.

Staging of Pressure Sores

- **Stage 1** - Intact skin with a localized area of nonblanchable redness. Presence of blanchable redness or changes in sensation, temperature, or firmness may precede visual

changes. In dark skin this may not be visible and may only show as a color change.

- **Stage 2** - Partial-thickness skin loss with exposed dermis. It may also present as an intact or ruptured serum-filled blister. Fat and deeper tissues are not visible, and granulation tissue, slough and eschar are not present.

- **Stage 3** - Full-thickness skin loss, in which fat maybe visible but muscle, bone and tendon are not exposed. Granulation tissue, slough and eschar may be present. There may also be tunneling and undermining.

- **Stage 4 -** Full-thickness skin and tissue loss with directly exposed muscle, tendon, cartilage or bone. Slough or eschar present on parts of the wound. Undermining and tunneling is often present.

- **Unstageable** - Full-thickness skin and tissue loss in which the extent of tissue damage within the wound cannot be confirmed because the wound bed is covered by slough (yellow, tan, grey, green or brown) or eschar (brown, black, tan).

- **Deep Tissue Injury** – Purple or maroon localized area of discoloured intact skin. Unknown level of tissue injured below skin.

Assessment of Pressure Sores

HISTORY

- Onset and duration of pressure sores
- Presence of pain due to wound
- Co-morbidities
- Psychosocial issues

EXAMINATION

- Number, location, size (length, width, and depth)
- Presence of exudate, odor, sinus tracts, necrosis or eschar formation, tunneling, undermining, infection, healing and wound margins
- Stage of each pressure sore

Reassessment on every visit

Management of Pressure Sore

Management of pressure sores in palliative care depends on stage of the wound and goals of care of the patient as decided in consultation with patient and/or caregiver

PRESSURE WOUND CARE

Caregiver should be educated on care of pressure sores

CLEANSING- The wound should be cleansed with boiled water (after cooling) or normal saline. Hydrogen peroxide and povidone iodine solutions are not used as they destroy healthy granulation tissue.

DEBRIDEMENT- When needed conservative methods should be used, like autolytic debridement.

Debridement of black eschar that forms on heel pressure sore should not be done.

INFECTION MANAGEMENT-

Dressing- Moist environment is required for promoting healing in pressure sores. A wide variety of dressings are available and may be chosen according to cost and availability.

- Moist saline gauze dressings may be used especially in stage 2 ulcers when there is no slough
- Wounds with large tissue defects may be loosely filled with saline moistened gauze
- Hydrocolloid, alginate and foam dressings may also be used (high cost and not easily available)

Wound pain should be managed with analgesics prescribed according to WHO ladder. All preventive measures must continue.

REFERENCES

1. Bates-Jensen BM, Petch S. Pressure ulcers:prevention and management. In Ferrell BR et al (eds). Oxford Textbook of Palliative Nursing 4th ed. Oxford, OUP. pp 297
2. Grocott P, Gethin G, Probst S. Skin problems in palliative care. In Hanks G et al (eds). Oxford Textbook of Palliative Medicine 5th ed. Oxford. OUP.pp 715-723.
3. Bluestein D,Javaheri A. Pressure ulcers: prevention, evaluation and management. Am Fam Physician. 2008; 78(10):1186-1194.
4. Choo J, Nixon J, Nelson A, McGinnis E. Autolytic debridement for pressure ulcers. Cochrane Database Syst Rev. 2019;2019(6):CD011331. Published 2019 Jun 17.
5. National Pressure Ulcer Advisory Panel, European Pressure Ulcer Advisory Panel and Pan Pacific Pressure Injury Alliance. Prevention and Treatment of Pressure Ulcers: Quick Reference Guide. Emily Haesler (Ed.). Cambridge Media: Osborne Park, Western Australia; 2014.

D. CARE OF BEDRIDDEN PATIENTS

Bedridden patients are those who are confined to bed for majority of the time due to illness or debility. Some bedridden patients may also be unconscious increasing the care required.

Common problems bedridden patients suffer from are:

- Eye infections
- Oral ulcers/thrush
- Dry skin
- Pressure sores
- Constipation
- UTI especially in those who catheterized
- Respiratory tract infection
- Venous thrombosis
- Malnutrition
- Psychological problems

Care of a bedridden patient aims at prevention of problems, comfort, rehabilitation and where possible, cure.

Involvement and education of informal caregiver is important for successful care of a bedridden patient in the homecare setting.

Assessment

HISTORY

Cause for the patient's current condition
Symptoms- pain, constipation, vomiting
Co-morbidities
Medication history
Dietary history
Care being provided

EXAMINATION

Mouth - for stomatitis/thrush
Eyes, ears- for any discharge/ infection
Skin- rash, bruising, over bony prominences for pressure sores,
Presence of tracheostomy, nasogastric (NG) or PEG tube, urinary catheter, ostomy
Extent of mobility- walks with support to bathroom, can turn in bed, immobile

COMPONENTS OF CARE

Personal hygiene
Nutrition
Exercise

PERSONAL HYGIENE

Good hygiene promote wellbeing in the patient.

MOUTH CARE

The homecare nurse must assess the mouth for dryness, coated tongue, ulcers, oral thrush on every visit.
Conscious patients may be assisted in their mouth care. In unconscious patients the caregiver should be empowered by demonstrating the procedure. A solution of sodium bicarbonate or salt may be used.

EYE CARE

The most common problem of the eyes is secretions that dry on the lashes or corners of the eye.. This may need to be softened and wiped away. Warm water may be used for this. Each eye should be cleaned from the inner to the outer canthus with separate swabs.

CARE OF NOSE AND EARS

The nose and ears need minimal care in the daily life. Excessive accumulation of secretions makes the patient to sniff and blow the nose. External crusted secretions should be removed with a wet cloth or a cotton applicator moistened with oil, normal saline or water.

SKIN CARE

Sponging and bed bath should be demonstrated to the caregiver.
Patient should be sponged or bathed daily using mild soap and water and skin should be dried thoroughly.

- Special care should be taken while cleaning and drying perineal area and skin folds.
- The hands and feet should be washed by placing them in the basin because it allows for thorough cleaning of the finger nails and toe nails
- The skin should then be moisturized with moisturizing cream/lotion/coconut oil and this should be done twice a day.
- In incontinent patients regular diaper change is required and the area should be cleaned well and emollient applied after each change. For rash due to incontinence zinc oxide cream may be applied.

Nails should be trimmed regularly.
While bathing or sponging the patient the skin should be inspected for early signs of pressure sores
Rubbing alcohol or powder should not be applied to the skin

Prevention of pressure sores (refer to pressure sores guideline)

- Regular turning every 2-3 hrs by caregiver.
- Using an alternating pressure air mattress – frequency of turning may be reduced to every 4-5 hours. If the air mattress causes significant discomfort or pain regular turning every 2-3 hours may be a better option
- Pillow-bridging- placing pillows to take off pressure on bony prominences and other areas vulnerable to pressure sores
- Reducing shear and friction
    A draw sheet may be used to pull up or position a patient in bed.
    The bed sheet should be kept free of wrinkles
    The head end of the bed should not be elevated more than 30 degrees

HAIR CARE

The hair should be washed regularly and brushed to prevent it from getting tangled and matted.
The scalp should be massaged to promote circulation
The hair may be trimmed at regular intervals after taking the patient's permission

PERINEAL CARE

The perineal area is prone to the growth of pathogenic organisms because it is warm, moist and not well ventilated. Thorough cleaning is essential to prevent infections, malodour and to promote comfort. Perineum should be cleaned after each urination and defection.

URINARY CATHETER CARE

- The outer surface of the catheter should be cleaned daily with soap and water or betadine
- Urobag should be kept below the waist level and the urobag cap should be kept closed
- Foley's catheter should to be changed once a month and silicon catheter once in 2-3 months.
- If the catheter gets blocked a bladder wash should be done

BOWEL CARE

Alteration in bowel function is common in the terminally ill. Constipation is more common than Diarrhoea. Efficient bowel management may alleviate distress. Bowel function should be assessed on every home visit. (See guidelines on constipation and diarrhoea)

CARE OF TRACHEOSTOMY TUBE

- Some patients may have a tracheotomy tube and the caregiver should be taught how to care for the skin around the tracheotomy tube and change the tie.
- The homecare nurse may change the tube once week for cleaning. The caregiver may also be taught how to change the tube
- Skin care- The skin around the tracheostomy tube should be cleaned with saline soaked gauze.
- Then to protect the skin a gauze piece which is slit in the middle should be placed between the tube and skin (Vaseline gauze can also be used).
- The tie is used to fix the tube in position and it should be changed when it is dirty. It should not be tied very tight nor too loose. A one-finger gap should be maintained between the tie and the skin.
- Suction should only be done if excessive secretions are present and the caregiver should be trained to do this. Suction should not be done for more than 5 seconds at a stretch.
- A wet sterile gauze on the top of the tracheostomy tube as this helps to humidify the inhaled air and filter the dust.

Nutrition

Decreased oral intake is common in patients with a terminal illness.
Caregivers should be advised not to force feed but provide frequent small meals and foods which the patient likes.
Nutritional supplements may also be given.
Some patients may have nasogastric tubes or PEG tubes and will be on a liquid diet
The homecare nurse should educate the caregiver on nutritious foods that may be given in liquid form.

Exercise

Exercise helps to prevent muscle retraction and decrease in range of motion

- Passive and active movements may be carried out depending on patient's ability and mobility and as long as they do not cause discomfort.

REFERENCES

1. Handicap International – Training of Physiotherapists and Doctors in Hospitals. PT Protocol for Bedridden Patients.
2. Retrieved online from http://www.hiproweb.org/fileadmin/cdroms/pta/TMFMT_4_14Bedridden_patients.pdf on 25 November 2021.

Care of the Dying Patient

A. APPROACH TO CARE OF A DYING PATIENT

Focus is on symptom management, psychosocial and spiritual distress, functional decline, communication and decision-making.

Ensuring the best possible quality of life for patient.
Supporting the patient and family during the illness and after the patient's death.

Assessment

It is important to recognize and diagnose the terminal phase. The deterioration could also be due to reversible causes and these should be excluded- delirium, infection, dehydration, opioid toxicity, hypercalcemia, hypoglycemia, hyperglycemia.

Recognizing the terminal phase

There is a period of irreversible decline in functional status before death which may last from a few hours to days and occasionally weeks. Symptoms which indicate onset of terminal phase-

- Increased weakness and fatigue - patients become bed bound
- Minimal intake of food and drink
- Difficulty in swallowing, especially solids and unable to swallow tablets
- Increased drowsiness – patients sleep for most of the day
- Changes in breathing pattern- Cheyne-Stokes, rapid shallow
- Refractory delirium
- Reduced urine output

In cancer patients it is often possible to identify the terminal phase. In other chronic diseases this may be difficult as there may periodic exacerbations from which the patient may recover fully or partially.

Communication with patient and family

- Effective communication and involvement of patient and/or family in decision-making is important
- Recognition of terminal phase should be communicated empathetically to the family and/or patient. Prognosis and its uncertainty should be discussed

- There should be a discussion on goals of care, place of care, treatment goals and cardio-pulmonary resuscitation (CPR). CPR may prolong but will not reverse the dying process. Patients and families may not necessarily understand this so it should be discussed.

The patient and/or family should be prepared for the terminal phase and end-of-life and what to expect.
They should be reassured that all symptom management and comfort care will continue with regular review and reassessment.

Management

All symptoms, psychosocial, emotional and information needs of the patient and family should be actively managed.

There should be a regular review and ongoing assessment. The homecare team should make frequent visits (2-5visits/week) and review on phone once a day.

The patient and caregivers may contact the homecare doctor or nurse at any time during out-of-hours.

Medications and routes of drug administration

- All medications should be reviewed and non-essential drugs (thyroxine, iron, calcium, vitamins) stopped
- Continuation of anti-hypertensives, anti-diabetic and ant-anginal drugs should be guided by clinical assessment of need. They may be discontinued in final days
- All drugs for symptom management should continue
- Anticipatory prescription drugs ('as needed' medications) should be with the patient

ROUTES OF DRUG ADMINISTRATION

Oral route may not be possible because of swallowing dysfunction, altered consciousness, nausea, vomiting or bowel obstruction.
Various routes of medication may be used

- Oral route if possible
- Sublingual route may be used for anxiolytics – lorazepam
- SC route is suitable for most drugs used for symptom management

  The homecare team should place a SC cannula and teach the family caregiver to give bolus SC medications.

- Transdermal route- Fentanyl or Buprenorphine TD patches may be used for pain management

Nutrition and hydration

- In the terminal phase patients don't benefit from enteral or parenteral nutrition and this should be explained to family caregivers.
- Patients who can swallow should be encouraged to take liquids and frequent small meals. Patients may be given to their favorite foods.
- In the last few days patients may take only sips of fluid or stop swallowing altogether. Teach and encourage the family caregivers to provide good mouth care to prevent dry mouth which is distressing for patients.
- When patient is no longer able to swallow, family caregivers are often distressed and may insist on artificial hydration. It should be explained to them that hydration may worsen oedema, ascites and respiratory secretions.
- If families still want hydration due to cultural reasons and depending on goals of care and preferences of patient and caregiver, small amounts of fluid (500ml NS/day) may be given SC or IV under supervision.

Symptom management in the last days of life

PAIN

- Pain should be assessed on every visit
- Patients on analgesics should continue those prescribed orally and dose should be titrated according to pain intensity
- Some patients develop pain for the first time during terminal phase. Pain should be managed according to WHO ladder.

If oral route is no longer available drugs may be given SC
NSAIDs- Inj diclofenac 50mg/ml – given 50mg SC bd or tds
Diclofenac TD patch 100mg and 200mg -one patch for 24hr
Opioids- Inj Tramadol 50mg/ml given tds
Inj Morphine 15mg/ml – convert 24 hour oral dose to 24 hour SC dose
Patients on TD Fentanyl or Buprenorphine may continue these

DELIRIUM:

Assess for reversible causes and treat them- urinary retention, constipation, pain, dehydration
Non-pharmacological measures will also help

- Explain cause and likely course to patients and/or caregivers, relatives
- The patient's room should be quiet, well lit, have familiar objects, with clock and calendar for orientation.
- A soft light should be on during the night to avoid confusion and anxiety if the patient wakes up.
- Encourage patient to drink fluids if possible
- No physical restraints

PHARMACOLOGICAL

Tab Haloperidol start with 0.5-1.5mg PO and repeat 1-2 hrly till patient calm
Inj Haloperidol 5 mg/ml- 0.5-1.5mg given SC if patient unable to take orally
For Agitated Delirium/Terminal Agitation:
Tab Lorazepam 1mg – 0.5-1mg SL should be given with haloperidol
or
Inj Lorazepam 1mg/ml – 1mg SC stat

BREATHLESSNESS

- Fan on the face, opening windows, upright position.
- If patient is hypoxic breathlessness will improve with oxygen may be given through nasal prongs.

Opioids – In opioid naïve patient- Tab Morphine – 2.5mg stat and upto q6h
If patient is already on morphine increase the the q4h dose by 50-100%.
If patient has intermittent breathlessness Tab Morphine 2.5mg may be given prn.

NAUSEA AND VOMITING

Metoclopramide 10mg PO or SC tds
Haloperidol 1.5mg-3mg PO bd or 1mg- 2mg SC bd

RESPIRATORY SECRETIONS

These may be prevented by avoiding artificial hydration in the terminal phase
Non-pharmacological management - Patient's position should be changed- turning laterally or putting the head down.
Pharmacological management- Inj hyoscine butylbromide 20mg SC 2-4 hrly; Maximum dose 120mg/24hr
Inj Glycopyrrolate 0.2mg SC 6-8 hrly

URINARY RETENTION AND CONSTIPATION

Both these conditions may be a cause of delirium or restlessness in terminal phase and therefore have to be managed
For urinary retention catheterization should be done and for constipation, depending on severity, suppositories or enema may be given.

TERMINAL HAEMORRHAGE

Some patients are at risk of a terminal haemorrhage and caregivers should be prepared for this.
Sedation should be prescribed in advance for this- Tab Lorazepam 1mg SL

NURSING CARE

Good nursing care should be provided for patient's comfort
Personal hygiene
Mouth care
Skin care for prevention of pressure sores
The homecare team should provide complete support the caregivers in their care of the patient during this period.

B. ANTICIPATORY PRESCRIBING AT END-OF-LIFE

Patients in the last few days of life may develop a number of symptoms within that short period. In the homecare setting it is useful if 'as needed' or anticipatory medication is available with the patient so that it may be given without any delay. This avoids unnecessary hospitalization at these patients.

When a homecare team determines that a patient is in the terminal phase this news should be empathetically conveyed to the family caregivers.

The homecare team should prepare the family caregivers for the terminal phase by educating them on what to expect. They should educate them on the symptoms the patient may have and what medication should be given.

All drugs that could be required for symptom management should be left with the patient along with a prescription their use.

If patient is able to swallow, oral drugs may be left with the patient.
As swallowing is often impaired parenteral drugs should be left with the patient and the homecare nurse should affix a scalp vein cannula subcutaneously. She should also teach the family caregiver to inject bolus doses.
The family caregivers should be advised to call up the homecare doctor or nurse if any symptoms occur so as to confirm the medication and dose to be given.
Sufficient quantity of parenteral medication should be left to last for 3-4 days so that patients will not be rushed to hospital over weekends.
Some patients and caregivers are unwilling for parenteral drugs. In such patients if oral route is not available SL or rectal route may be used.

ANTICIPATORY PRESCRIPTION - ORAL DRUGS

SYMPTOM	DRUG	DOSE	REMARKS
Pain	Morphine 10mg	2.5 - 5mg q4h/q6h PO	If patient on oral morphine convert to SC dose. prn dose is 1/6th – 1/10th of 24hr dose
Agitation	Lorazepam 1mg	0.5mg – 1mg SL	Lorazepam is easily available in homecare setting and may be given SL
Delirium	Haloperidol 1.5mg	0.5mg – 1.5mg PO	May be given stat then every 2 hour till patient is calm or sedated
Breathlessness	Morphine 10mg	2.5 -5mg PO prn	If patient is on oral morphine
Nausea & Vomiting	Metoclopramide OR Haloperidol	10mg PO stat & bd or tds 1.5mg PO stat & od or bd	Easy availability of metoclopramide

ANTICIPATORY PRESCRIPTION – PARENTERAL DRUGS

SYMPTOM	DRUG	DOSE	REMARKS
Pain	Morphine 15mg/ml	1.5mg - 3mg SC prn	If patient on oral morphine convert to SC dose. prn dose is 1/6th – 1/10th of 24hr dose.
Agitation	Lorazepam 1mg OR Midazolam	0.5mg – 1mg SL 2-5 - 5mg SC prn	Lorazepam is easily available in homecare setting and may be given SL

Delirium	Haloperidol 5mg/ml	1.5mg – 3mg SC	May be given stat and then hs or bd and prn
Breathlessness	Morphine 15mg/ml	1mg – 2mg SC prn	
Nausea & Vomiting	Metoclopramide OR Haloperidol	10mg SC stat & bd ortds 1 mg SC stat & od or bd	Metoclopramide is easily available
Respiratory secretions	Hyoscine Butylbromide	20mg SC stat & 2-4 hrly	This drug is poorly absorbed if given orally and should be given SC

REFERENCES

1. Gomes, B and Higginson, I J Factors influencing death at home in terminally ill patients with cancer: systematic review.. BMJ 2006: 515-518.
2. Adam, J. The last 48 hours. In Fallon M, Hanks G (eds).ABC of Palliative Care BMJ, Oxford (pp. 44-47).
3. Lacey, J. Management of the actively dying patient. In Hanks G et al (eds). Oxford Textbook of Palliative Medicine 5th ed. Oxford. OUP.pp 1125-1133.
4. Crawford GB, Dzierżanowski T, Hauser K et al.Care of the adult cancer patient at the end of life: ESMO Clinical Practice Guidelines. ESMO Open. 2021; 6(4):1-13.

Subcutaneous Fluids and Drugs

When the oral route is unavailable to patients the subcutaneous (SC) route is the preferred method of drug administration for both fluids and drugs especially in the homecare setting.

IV fluids and drugs should be avoided because they are invasive and no more effective than the subcutaneous route.

Intramuscular (IM) injections should be avoided, as they are painful, particularly in patients who are cachectic.

ADVANTAGES

- Easy to use and few complications
- Can be taught to family caregivers and easy to manage in homecare setting
- Increased patient comfort, avoiding the need for repeated injections
- Suitable for patients who are very drowsy, comatose or semi-comatose
- Avoids the administration of an excessive number of tablets
- Cannula can be left in place for 7days if no redness/inflammation, therefore less demanding on nursing resources.
- Infusion can be stopped and started with little risk of thrombosis or bleeding

INDICATIONS

SC route can be used in following situations:

- Severe dysphagia /swallowing difficulties
- EoL when swallowing impaired
- Mouth, throat and oesophageal lesions
- Intestinal obstruction
- Profound weakness
- Unacceptable number of oral medications or volumes of syrups which make ingestion difficult
- Unconscious patient
- Intractable symptoms that are not well controlled with oral drugs
- Rectal route is inappropriate.

COMPLICATIONS

- Possible inflammation or irritation at infusion site
- Possible leakage of SC site
- Possible allergic reaction (rare occurrence)
- Caregiver compliance

SUBCUTANEOUS INSERTION SITES

Anterior aspect of the upper arms
Anterior abdominal wall lateral to umbilicus
Anterior aspect of the thigh
The scapular region - if the patient is distressed and/or agitated
Infraclavicular region of anterior chest wall above the breast

SITES NOT SUITABLE FOR SC CANNULA

Skin folds and breast tissue
Directly over a tumour site
Lymphoedematous limb or oedema – absorption may be reduced
The abdominal wall if ascites present
Bony prominences – little SC tissue, absorption reduced
Previously irradiated skin – skin may be sclerosed, poor blood supply
Sites near a joint – uncomfortable, increased risk of displacement
Infected, broken or bruised skin

FLUIDS GIVEN SC

Fluids - Normal saline, dextrose saline

ASSESSMENT FOR SC FLUIDS OR DRUGS

Patients with persistent vomiting, bowel obstruction may require SC fluids and medications.
Patients in the terminal phase with impaired swallowing may require SC drugs for symptom control.

MANAGEMENT OF SC INFUSION AND DRUGS

SC Infusion

- The SC cannula (scalp vein or butterfly cannula) should be inserted by the homecare nurse or doctor using a 23G or 24G cannula, the SC infusion should be connected and infusion rate adjusted.

- The family caregiver should be taught how to stop the infusion and disconnect the SC infusion set from the cannula. If the patient has been advised drugs by SC route the caregiver should also be taught to inject these into the cannula.
- The caregiver should be asked to observe the skin around the cannula for any redness. If any redness is observed the cannula should be removed immediately. The homecare nurse or doctor should be informed on phone if this occurs.
- If the cannula gets blocked or blood appears in the tubing it needs to be changed
- The cannula can be left in place for 5-7 days.
- 1-2L of fluid may be given SC/24hrs. 500ml fluid should be given in 6-8 hours though it can also be given faster if required.
- If a faster infusion rate is required inj hyaluronidase should first be given SC to increase absorption rate.
- When SC drugs are prescribed a chart of the drugs with timings should be made for the caregiver.

REFERENCES

1. Kamal AH, Bruero E. Hypodermoclysis. Palliative Care Network of Wisconsin. http://www.mypcnow.org/fast-fact/hypodermoclysis/ (accessed 26 November 2021).

Counselling in Palliative Care

A. COMMUNICATION

Importance of communication in palliative care

Everyone with Cancer is undergoing a journey and has a story to tell. Encouraging people with cancer to tell their story is often therapeutic in itself, helps clarify the person's need and encourages empathetic understanding. Successful symptom control in palliative care requires effective communication. People feel better if someone listens to their concerns and have been understood. Thus, active listening skills are important. They are the key to good communication.

The following methods help to enhance listening skills:

- Greeting (attending skills)
- Asking open-ended questions
- Encourage talking
- Maintain eye contact
- Allow a 'brief' period of silence
- Avoid unnecessary interruptions
- Show them we are listening
- Empathize with them
- Prioritize the agenda
- Summarize and planning for the next visit.

Essential components in communication

Rapport building: Establishing rapport with patients is very important in palliative care so that they feel comfortable and relaxed. Rapport builds a connection between the patient and the counsellor. Successful counselling needs three core conditions in order to build a relationship: Unconditional positive regard, congruence/genuineness, and empathy as proposed by Carl Rogers (1957).

1. **Unconditional positive Regard:** This means that the person should be accepted the way they are (irrespective of caste, creed, gender, social status, age, education etc.) with no terms and conditions attached. Whatever thoughts emotions, or behaviour, ideas the person may express, it cannot disqualify them from getting a positive response from the counsellor. For example, patients may be thinking

negatively or may not be able to express themselves properly, yet, the counsellor must accept them as they are.

2. **Congruence/genuineness:** It means the counsellor is genuine in their expression. The Counsellor should behave like a genuine person, no artificial behaviour should be shown on their part.

3. **Empathy:** it means Understanding another person's state of mind/world, or the capacity to recognise the emotion. It is often characterized as the ability to "put oneself into another person's shoes or in some way experience the outlook or emotions of another being within oneself. Empathy is to sense the other person's private world as if it is your own, but without losing the "as if" quality. It is the capacity to "feel with" not to "feel for". Karl Rogers states empathy is "to sense the client's private world as if it is your own, but without losing the "as if" quality." When a counsellor shows empathy, they acknowledge and try to understand the subjective world of the patient.

It is believed that people are able to explore a wider range of belief and feeling if they are provided with a nurturing atmosphere. With the counselling intervention, the person starts accepting themselves and the reality as it. This belief in themselves helps them understand their inner selves and enables them to look at their life problems in a better way.

So, the role of counselling and good communication is essential to help them to grow and self-actualise.

How a counsellor communicates in CanSupport?

The home care team of CanSupport consists of a doctor, nurse and a counsellor. On the first day of a home visit to a patient's house, the team counsellor introduces the team and makes a special mention of the counsellor with whom the patient and the family members can discuss their stressors, concerns, feelings and anything that is worrying them. This gives an opening to the family and they begin to feel that they can share their concerns with the counsellor.

On the first day of the visit the counsellor observes the family and assesses who is the main caregiver with whom a conversation can be started. Listening is the most important part of communication, as is confidentiality. The counsellor must assure the patient and the family that full confidentiality will be maintained.

Palliative Care Communication requires listening and making therapeutic relationships based on truthfulness. Communication should always be patient centered, as every patient is unique and having their own subjective experience of a journey, illness and life. Communication is a two-way process. Therefore, a counsellor communicates verbally by using phrases like "please tell me more" and, by paraphrasing what the patient or the caregiver is sharing. Communication is also Non-verbal. It involves maintaining eye contact, nodding their head, and keeping an open body posture and leaning towards the person. The counsellor does not try to rescue the patient by giving answers to their problems. Such counselling should always be non-directive i.e. counsellor gives information about all options available and patient / caregiver will choose the best available option for themselves. (Informed decision making) Most importantly, the counsellor is non-judgmental.

Points to remember while communicating

- Communication has to be clear and loud
- Communicate with compassion and empathy
- Communication must be sensitive to the individual
- Communication must be through open ended questions
- A good communicator will use active listening
- Communication must respect confidentiality
- Good communication requires knowledge, attitude and skills
- A good communicator will ask time and again- "what else can I do for you?"

B. BREAKING BAD NEWS

Breaking bad news is an important aspect of communication and it should be done in such a manner that it reduces the impact of bad news and facilitates understanding and acceptance. It should be tailored according to the need of the concerned individual. If the bad news is not being delivered properly then it may lead to immediate or long term damage.

Before breaking bad news, it is important to acquire the skill of doing so and also how to respond to the patient's emotional reaction after hearing about the bad news.

So, we must follow some protocols to do the same. There are many Acronyms of breaking bad news protocols.

Breaking bad news should be done when:
- Patient is emotionally stable and relaxed and all physical symptoms are managed.
- When patients want to know about their health information.
-

If patient is emotionally hostile, we can defer the breaking of bad news.
If patient does not want to know, encourage them to ask, assuring them of our availability

Here we will discuss the SPIKES (6 step) protocol for breaking bad news.

i. **S Setting**

The setting of the meeting is important. A proper sitting arrangement is important so that the person feels comfortable. In Home care setting the bedside is the best place for breaking bad news as it is the most secure place for the patient. If they want family or close friends to be there in support, make sure that these people are included as well. It is not necessary to rush into breaking the news, take a moment to connect and build rapport with your patient by showing empathy. Whoever is breaking the bad news should be well informed about all medical details of the patient

ii. **P Perception**

Perception refers to the patient's current level of awareness of their medical issue and what they think the outcome is likely to be. It is important to do more listening than talking at this stage; there is no need to challenge the patient for unrealistic hopes at this point.

iii. **I Invitation**

At this stage, ask your patient if they want to know the details of their condition or the likely treatment (seeking permission of the patient). Meet your patient where they are; if they are not ready for details, it is not necessary to force them to listen. The SPIKES method acknowledges that each patient has a right not to know details if they are not ready for them. Wait for permission from your patient before proceeding with the news.

iv. **K Knowledge**

Now you are sharing knowledge and information with your patient. First give the warning shot ("you may say that your reports are not good", "your reports are not as good as we hoped them to be" etc.) so that patient will be prepared for the information and the emotional impact likely to be there. Your patient will need you to speak in plain and simple terms. Do not use medical jargon. Consider the person before you; have they understood what you have said? Do not rush this part of the protocol.

v. **E Emotion**

The sharing of bad news is emotional for both health care professional (HCP) and patient. Create space for your patient to express emotion and practice deep empathy. Encourage patient to share their feelings and concerns. Put yourself in their shoes by identifying with their reaction - sadness, shock, denial—and help them to identify it too. Don't give false reassurance like "everything will be all right". Don't give platitudes like "be strong"," be Courageous and be a fighter" as such statements give additional burden on the patient.

vi. **S Strategy and Summary**

End the meeting on an intentional note by explaining what will come next. Make strategy with involvement of patient and care giver for future care and plan, because making plan to act further makes patient more relaxed and de-stressed Summarize your thoughts and your understanding of the patient's reaction, and set expectations for the next appointment.

CanSupport counsellors follows the SPIKES protocol for breaking bad news. The patient has the right to know about their disease (autonomy/self-determination) so that he can take decisions regarding treatment or symptom management. But in the Indian scenario the family usually takes the decision for the patient. Caregivers feel

that if the patient comes to know about their disease, they may give up, will be in shock, may become withdrawn, and may go into depression, and they (care givers) will be unable to manage the emotional reactions. The counsellor understands that the intention of the caregivers is out of concern and to protect their loved one from further emotional pain and respond accordingly.

The counsellor first tries to find out how much the patient knows about his illness. If the patient does not know much about their illness, the counsellors tries to find out why the family does not want to disclose the truth, and validates the reason. The counsellor acknowledges the concern of the caregiver.

Breaking Bad news should be done with patient centered and culturally sensitive approach. Considering the values and belief system of the patient and family. Indian society is a collective society with shared autonomy, unlike the West, which is individual focussed society. It should not be done in an algorithmic way, but with common sense.

Points to remember

Good Communication is crucial for relieving total suffering of patients and their families. The skills needed to communicate well with patients are not so complex, but must be learned and practiced. they can make a significant difference in the quality of life of both patients and families. But poor communication can lead to increased stress for professionals and distress for caregivers and patient too.

C. COLLUSION

A secret agreement or cooperation between two or more people with the intention of keeping the truth or the facts from the patient in health care. Collusion implies withholding information (about the diagnosis, prognosis, and medical details etc. about the person who is ill).

Collusion also means that relevant and complete medical information is selectively or not at all disclosed to patients and/or relatives.

Types of Collusion

Health care professionals colluding with relatives keeping the patient in dark.
Health care professional colluding with patient and not informing the family or relatives.

Collusion generally happens because the doctor and the caregiver do not know how to manage the situation.

The intention of the doctor and the caregiver is to protect the patient. They think that the patient may go into a shock or depression if the truth is told.

Generally, the reasons for collusion as perceived by family members are-

- The patient may breakdown
- May go into a depression (withdrawn)
- May give up
- May not co-operate for treatment
- May think of dying or of committing suicide
- May stop taking food and water
- May have anger issues
- May ask to visit other hospitals for treatment
- May increase stress and accelerate disease progression

COST OF COLLUSION

- Patient is unable to make informed choices for their treatment therefore autonomy is compromised.
- The patient will be left guessing about their diagnosis and prognosis and may think they are worse off than they actually are. They may be put under a great deal of fear and stress

and feel cut off from their loved ones. Consequently, they may feel discouraged and alone and may abstain from talking and withdraw themselves. This may in turn lead to anger towards the treating doctor and the caregiver.
- Because of not telling the truth the patient will not be able to take decisions like preparing a will, settling their financial affairs and unfinished business, etc.
- The caregiver on the other hand too will be burdened from having to lie and may give false hopes to the patient.
- There might be non-compliance with treatment.
- Both the patient and family lose the time they have to laugh and cry together, build new memories as well as cherish those that exist .
- Blocked grief.
- Social isolation.
- Loss of trust.

HOW TO DEAL WITH COLLUSION
- First and foremost, assess and identify the presence of collusion.
- Acknowledge collusion.
- Explore the reasons for collusion and validate them.
- Help family members to realize the cost of collusion as mentioned above.
- Check the level of awareness of the caregiver and the patient as to how much each understands about the stage of the disease.
- Encourage them to talk. Discuss the decision-making right of the patient, their right to withdraw from treatment and their right to plan for the future.
- Give confidence to the caregiver that they are not alone and that truth telling will help the patient to get involved in their (informed decision making) treatment and avoid unrealistic hope.
- Suggest to the caregiver that if they were in a similar position what would they want? This question will help create a shift in thinking.

In CanSupport's home care practice it is found that, most patients would like to know the truth and that they are already aware that something serious is happening.

In CanSupport the team recognises that actually the family does not want the patient to be told about his disease not only because they fear their loved one will go into a shock or give up, but also because they don't know how to manage the situation. Here the role of a counsellor comes into play. The counsellor speaks with the caregiver about their concerns. The team also specifies that they are all experienced and trained

in how to break the news and manage the aftermath. After listening to the concerns of the family, the counsellor explains how important it is to disclose the truth to the patient. They are assured that the news will be broken very gradually with pace of the patients, the information will be given according to how much the patient wants to know about their disease. Generally, the patients know about their disease but is afraid to speak with their loved ones so as not to upset them.

The counsellor also discusses with the family about wishes of the patient. These may be practical needs such as sharing information pertaining to their bank account or property matters. They might also want to meet someone to say goodbye. Often there are forgiveness and reconciliation issues that need to be addressed. They may want to get more involved in their treatment process.

It is desirable that collusion be broken with the consent of the family. The family generally does agree to break the collusion and subsequently the breaking the news is done very gently taking time so that all the concerns of the family are taken care of.

There are exceptions made however for very old patients and very young children.

CASE STUDY
All names have been changed to protect privacy

Alam (name changed) a 48-year-old male patient had been diagnosed with 4th stage cancer of the lungs a few months before he was visited by the CanSupport home care team. Alam lived in a joint family with his three brothers. He had three school going children and his wife was the main caregiver. The cancer had spread to his brain, bones and lymph nodes. As the cancer was diagnosed during the Covid – 19 lockdown period the hospital did not start his chemotherapy and radiotherapy.

When the team visited the patient, he had severe back pain. The patient was very drowsy. The wife looked very worried and his brothers were very careful that the team did not interact with the patient's wife (collusion). They asked her to go into the other room and they whispered in the team's ears that the patient and his wife do not know about the prognosis of the disease and that they do not want team to tell the patient's wife about the prognosis.

As the patient was very serious, the team initially listened to the family and concentrated on managing the symptoms of the patient. The counsellor then spoke with the family members and asked them why they didn't want to disclose the prognosis to his wife.

There was a discussion about the positive side of telling the truth. The family felt that if the truth was disclosed the wife would not be able to manage the situation and may go into depression. She would then not be able to take care of her children and the patient. The team listened patiently and respectfully to the family and then explained the reasons why the patient, who was currently very drowsy, and his wife should know the truth.

The points discussed with the family were the following;

1. When the patient becomes more alert, he is likely to ask why his treatment has stopped? What will you say?
2. If he knew the truth, he would be able to plan and discuss with the family the future of his wife and children.
3. It is likely that he will want to finish any unfinished business-like sharing information about his account, his life insurance policies as well as other important house hold papers.
4. Once told, he will be able to make informed choices about continuing with his treatment or not, or want to adhere with Palliative Care.
5. He wants to fulfil his last wishes or some religious rituals

The family listened to the team and agreed to think about it. The team reassured them that they were available on phone for support and that it was only with the approval of the family that the decision to tell or not to tell the patient and his wife would be taken.

The next day the team received a call saying that the family had discussed the issue among themselves and had come to the conclusion that the team together with the family would disclose the truth. The doctor, nurse and counsellor visited the family after two days. They were pleased to see that the patient was more alert because his symptoms had been well managed by the team.

The truth was disclosed to Alam and his wife very slowly and answers were given to all their queries. The family cried together and Alam was able to discuss with his family and his wife matters relating to his bank account, his life insurance policy and a plot of land that he had purchased to secure his family's future. Later the family helped him to get the land registered his wife's name.

The family thanked the team for helping them resume communication with one another and shared how none of them was now carrying the guilt of hiding information from Alam and his wife. Alam and his wife were also happy and soon after Alam passed away peacefully in his bed.

D. PSYCHO-SOCIAL DISTRESS

What is Psycho-social Distress

Psychosocial distress is common in cancer patients; however, it is often unrecognized and it needs intervention. Patients can provide verbal and non-verbal information about their emotional state. Often patients do not reveal emotional issues as they believe it is not a health care professional's role to help with emotional concerns. Moreover, patients may normalize or somatise their feelings. Anxiety and depression can mimic physical symptoms of cancer or treatments and vice versa, and consequently emotional distress may go undetected.

Psychological distress can be described as

- Suffering
- Hopelessness
- An existential crisis or a spiritual crisis
- Undermining the capacity for pleasure
- Taking away a sense of meaning
- Diminishing the ability to connect with others
- Having a negative effect on quality of life
- Sadness
- Anxiety
- Worry
- Anger
- Fear
- Depression
- Shame
- Guilt
- Hopelessness/Uncertainty
- Loneliness/Isolation
- Sleeplessness

How counsellors can do psychological assessment –

An assessment tool is a distress thermometer which was made by NCCN (National Comprehensive Cancer Network). It has numbering from 0 to 10. The patient is asked to evaluate how much distress he has by placing their finger on the numeral that best describes it. If he places it on 5 then the distress he has is 5/10.

The emotional and psychological assessment of a patient can be done by:

1. Finding out about the family, is it a functional family or a dysfunctional family? Is the family supportive or non-supportive? What is the attitude of the caregiver towards the patient?
2. Is the patient withdrawn or easy to talk with?
3. Is the patient in shock or denial or are they hopeful? Have they adjusted to their illness or situation and are coping well?
4. Does the patient have any fears like fear of death, or fear of dying in pain, fear of leaving the family behind or fear of meeting with God?

Patients may experience spiritual distress as death approaches or any time during the cancer journey. It too needs to be assessed and if needed a spiritual guru's or chaplain's advice may be taken. The purpose is to help the patient attain peace of mind.

It is the all-embracing and holistic approach of palliative care that is helpful in managing depression or other psychological distresses.

How the CanSupport team helps the patient who are in psychological distress? Techniques such as active listening, using open ended questions to probe concerns and feelings, responding appropriately to patients' emotional cues, and a patient-centered counselling style can assist in detection of psychological distress. The use of screening tools administered prior to the consultation can also be useful.

In conclusion, the application of basic communication techniques helps in exploring of patients' emotional concerns. Counsellors, doctors and nurses should learn these techniques to improve the psychosocial care of their patients.

E. DEPRESSION IN CANCER PATIENTS

Depression is not just feeling sad. It is a serious mood experience that needs intervention It may cause severe problems that affect how you feel, think, and manage daily activities, such as sleeping, eating, and working. The core indicators of depression are said to be anhedonia, which refers to loss of interest or a loss of feeling of pleasure in activities that usually bring joy into the lives of people. It may feature sadness, difficulty in thinking and concentration or significant increase or decrease in appetite. It's important to understand the cognitive triad of depression in palliative care, i.e., helplessness, hopelessness, worthlessness which can result in suicidal ideation and attempt to suicide. It can either be short term or long term.

Likely causes of Palliative care patients going into depression can be - when they feel their pain and symptoms are not managed, disease is progressing, recurrence of disease, side effects of treatment, feeling of being a burden on their family, letting their family down, undignified life etc.

Prevention of depression in Palliative care

Good palliative care is the key strategy for preventing depression in patients. The palliative care approach integrates physical, psychological, social and spiritual care to manage symptoms and distress so to optimise quality of life. Effective assessment and management of physical symptoms, such as pain and fatigue are integral to palliative care and a prerequisite for preventing depression. It's very important that the risk factors for depression in palliative care be assessed such as lack of social support and poor performance status. Identifying patients at risk facilitates increased psychosocial support and sensitivity to the symptoms and signs of depression.

Communication should be non-judgemental and empathetic. Besides listening, involve the patient in treatment decisions by providing them appropriate information. Confidentiality, and privacy must be respected so that dignity is maintained. Open ended communication is important. Medical jargon should be avoided as far as possible. Facilitating communication between family members should not be neglected as it enhances the quality of relationships with significant others.

Provide patients and family members with information on the nature of treatment, likely side effects, and medications the patient can take so that the symptoms can be managed effectively. Physical symptoms should be assessed along with psychological,

emotional, social and spiritual concerns so that the depression can be reduced and quality of life enhanced.

Patients coping strategies should also be observed and when necessary new more effective strategies may be suggested so to help them regain a sense of control. Developing social relationships, finding meaning in events, joining faith and community groups etc. are ways to combat the isolation that often leads to depression.

Signs and Symptoms

Depression is associated with the following

1. Physical Symptoms like - Pain, fatigue, inability to sleep etc.
2. Increased desire for death or demand for assisted suicide.
3. Reduced compliance with treatment and lack of interest in activities
4. Putting off important health care decisions or plans.
5. Fear of prognosis or disease recurrence or of dying.
6. Complicated grief in family members.
7. Social isolation.
8. Family conflict
9. Financial difficulties
10. Loss of function, roles and relationships.
11. Dependency on others
12. Existential or spiritual distress
13. Persistent low mood and tearfulness.
14. Loss of appetite with unintentional weight loss or weight gain.
15. Increased or decreased sleep.
16. Loss of interest or pleasure in daily activities, social withdrawal.
17. Unable to concentrate
18. Reduced self-esteem and self-confidence
19. Reduced energy
20. Decrease in sexual functioning and desire or libido.

Identifying risk factors associated with depression can help diagnose and treat it early

Severity of Depression

Depression may be classified as:

Mild

Moderate

Severe also called "major"

A minimum period of at least two weeks is required to diagnose the severity of depression. Depression may be diagnosed clinically by a qualified doctor but it is important for counsellors to be able to identify early signs by screening and report them to the treating doctor in the team.

Mild depression involves more than a temporary feeling of sadness and can be difficult to identify.

In mild depression a person may experience:
- Sadness
- Irritability or anger
- Loss of appetite
- Loss of interest in activities which were once enjoyed.
- Lack of motivation
- Disturbed Sleep
- A sudden lack of interest in socializing
- Reduced energy levels
- Difficulty in concentration
- Reckless behaviour, such as alcohol abuse, use of drugs or gambling

Minimum Duration: 2 weeks (unless unusually severe and of rapid onset)

Moderate depression shares similar symptoms but it is one level up from mild depression.
It may cause:
- Problems with self esteem
- Reduced productivity
- Feelings of worthlessness
- Increased sensitivity
- Excessive worry
- Inability to socialise

Moderate depression is easier to diagnose than mild depression as the symptoms significantly impact daily living.
Minimum duration: 2 weeks.

Severe Depression has symptoms that are common with both mild and moderate depression, except that they are noticeably more severe. Episodes of severe depression may last for six months or longer.

A person may have
- Delusions for example a person may believe someone is out to get them or is mistreating them.
- Auditory hallucinations for example hearing sounds or noises that are not there
- Suicidal ideations or behaviour.

Minimum Duration: At least 2 weeks (severe intensity)

Depression assessment tools

CanSupport has been using GHQ – 12 (General Health Questionnaire) and PHQ – 9 (Patient Health Questionnaire) as a screening tool to assess depression.
In addition to the detection of depression it also helps to assess the effect of treatment on the symptoms of depression over time.

PHQ-9 scale (Patient Health questionnaire) can also be used to measure depression. This easy-to-use patient questionnaire is self-administered version of the PRIME-MD diagnostic instrument used for common mental disorders. PHQ-9 scores each of the nine questions between '0' (not at all) to '3' (nearly every day). It has been validated for use in primary health care. It is not a screening tool for depression but is used to monitor the severity of depression and the response to treatment.

Interventions for Depression by the CanSupport team

The doctor and the counsellor are well trained to assess depression in cancer patients. In patients with depression, psychological therapy, psychoeducation and antidepressant drugs are the mainstay of treatment. Important issues to consider include; the patient's diagnosis, prognosis, symptoms.

For mild depression the team uses guided self-help techniques or a brief psychological intervention. They also facilitate effective communication and social support.
For moderate depression the doctor prescribes antidepressants and psychological therapy is given by the counsellors.

For severe depression and to manage suicidal risk the team has a psychiatrist on board and the patient is referred to him.

The team provides patients with information about all treatment options. They listen to patients' preferences and consider the experience and outcome of previous

treatments. The team considers patients' likely life expectancy and the time required for treatment with anti-depressant to be effective. The patient is reviewed for side effects in the first week of prescribing antidepressant treatment. There is repeat assessment of patients' mood every 2 weeks to monitor response to treatment.

Therapies for managing depression:

COGNITIVE BEHAVIOURAL THERAPY (CBT) focuses on identifying and restructuring dysfunctional thought patterns. It is the most widely used and evaluated psychological therapy. CBT is a blend of cognitive therapy and behavioural therapy. CBT focuses on moods and thoughts. This therapy helps patient to deal with their depression.

PROBLEM-SOLVING THERAPY is a short, focused intervention that helps patients identify, discuss and resolve specific problems. Its brevity makes it a good choice for patients receiving palliative care.

OTHER THERAPIES (e.g., interpersonal therapy, couple therapy, group therapy, mindfulness-based therapy) may be beneficial for patients with advanced disease, but the evidence-base is limited.

Creative therapies (e.g., music and art therapy) may benefit patients by supporting emotional and spiritual expression and promoting relaxation, pain control and wellbeing.

Points to note:

- It is a process where practical advice is given to deal with the problem
- Always emphasize confidentiality.
- Set up your next visit before leaving
- Teach breathing exercise and yoga keeping in mind the situation of the patient. involve care givers

Assess suicide intent if they hint at harming themselves by asking questions like

- Have you been having thoughts of harming yourself lately?
- Are these thoughts coming repeatedly?
- Have you made any plans for carrying it out?
- Have you been feeling that nothing can be done to make things better?
- If the answers to all these questions is "yes" there is need to respond immediately
- Inform the family, the team is also obliged to inform their senior in CanSupport.

Conclusion

Depression is one of the important symptoms to identify and manage in palliative care as it improves quality of life even at the end of life. If the distress of the patient is well managed, the patient will be peaceful throughout his journey

Case Story (Depression)

All names have been changed to protect privacy
Anita (name changed) was a 46 years old female who had been diagnosed with metastatic ovarian cancer. Her main caregivers were her two daughters and husband. She was getting her treatment done from a private hospital. Her immediate family was supportive and caring.

ISSUES

1. She was depressed because there was no support from the extended family
2. She was angry all the time
3. She had a great deal of pain and felt fatigued, restless, irritable and was unable to perform her duties
4. She could not sleep at night and would cry at the slightest thing
5. She didn't want to speak with anyone

Anita showed symptoms of severe physical and mental pain.

When the teams visited the patient, she was lying down because of severe pain and was crying loudly. The doctor sat with Anita and examined her. He gave her pain medicine and soon her pain is relieved.

The counsellor started speaking with the patient with empathy. She expressed her anguish and said she was unable to control or stop her negative thoughts. Because she was bedridden she felt she was a burden on the family. Seeing her distress, she was screened for depression and it appeared she had moderate depression. The doctor started her on mild antidepressants. She was taught to do some deep breathing exercises too The counsellor even shared some breathing exercise videos which she could watch and use for practice.

The teams spoke with the family too. Understandably they were very distressed by seeing her in so much pain. After two weeks when her pain score came down she could smile again. The family also felt better. Depression when diagnosed at the right time and with timely interventions, improves the quality of life of patients.

F. SEXUALITY AND INTIMACY

Sexuality is an integral part of every human being, it's not just physical but also about self-esteem and one's social role. Together they define the identity of a person.

Intimacy is the ability to communicate and receive love Sexual intercourse is only a part of it. It meets a vital human need.

Sexuality and intimacy remain significant concerns during terminal illness. They are an important part of holistic care, psychosocial functioning and quality of life. Unfortunately, even palliative care setting patients are rarely given an opportunity to share sexuality related concerns with their health care providers.

Disease processes can drastically alter one's appearance, cause physical and emotional pain and effect libido and functionality. Unfortunately, these hindrances come at a time when many patients want to strengthen relationships with the one they love.

Why aren't we talking about this?

Healthcare professionals routinely discuss quality of life issues with patients however the literature suggests that this often does not include assessment of sexual functioning and intimacy concerns. Ninety percent healthcare professionals stated that discussing sexuality was part of the job yet only 2% said that they regularly spoke to patients about it (Hautamaki.K, et al, 2007).

The primary cause for change in sexual functioning and desire is usually change in body image and self-perception.

Perceived loss of attractiveness occurs because of:

i. Surgical procedures such as colostomy, mastectomy, catheters implants etc.
ii. Bodily changes causing - unpleasant odor, hair loss, changes in weight etc.
iii. Surgical intervention resulting in mutilating scars, removal of body parts, inflammation or swelling etc.
iv. Treatment related – Chemotherapy or Radiation side effects

Patients who internalize the assumptions that they are no longer attractive or desirable, may end up experiencing a self-fulfilling prophecy of decreased sexual activity and interest. This may result in reduced displays of affection and emotional disengagement

To counter this, it is necessary to highlight other attributes and challenge socially constructed assumptions linking body parts with self - worth, desirability and personhood.

However, be aware that this is a delicate subject and there may be cultural taboos that hold people back from discussing such matters. Gently explore but do not push or insist if you meet with resistance. Allow the person time to reflect and set the pace.

Interventions made by CanSupport teams

The CanSupport team knows that there will be a great deal of concern when the couple is young and one of the partners is affected by cancer. They have a discussion with both the partners after broaching the subject in a non-judgmental manner. The doctor discusses the medical aspect of ongoing treatments while the counselor pays attention to emotional concerns and fears.

In such circumstances the counsellor proposes that the couple try alternate methods of sexual expression and intimacy, like holding hands, giving special looks, hugging etc. alternate sexual positions. The purpose is to help align expectations with the reality of the disease so as to minimize the impact of barriers to patient and partner intimacy.

They need to realise that an absence of sexual intercourse does not necessarily preclude physical and emotional closeness.

The use of relaxation techniques and aromatherapy is encouraged as well as prosthetic aids such as wigs and prosthetic bras to enhance appearance.

Reassure the couple that kissing, stroking massaging and embracing won't cause physical harm and may actually help lead to relaxation and decreased pain. Having the partner help with bathing may be a non-threatening way to encourage touch if the partner fears causing pain or distress. In fact, some patients say that intimacy is enhanced with the illness: "We feel better and closer than before."
"We have become more intimate on other non-sexual levels"
Fatigue can decrease a person's ability to maintain their personal grooming. They may need help with showering, hair care and makeup. It is wise to consider strategies that require less effort such as having a hand mirror and grooming aids within easy reach. Partners too can be involved in providing personal care.

Mouth care is also paramount as oral issues can affect intimacy.

Maintaining the dignity of the patient is essential when providing intimate care.

The team ensures that symptoms such as pain, nausea and constipation are well managed. They encourage the patient to take medication for the above symptoms before starting sexual intimacy.

G. SPIRITUAL CARE IN PALLIATIVE CARE

Spiritual care is one of the most overlooked aspects of palliative care because it is so ill defined and misunderstood. More often spiritual care is seen as religious care, which trivialises and diminishes its true nature. Spirituality and religion are distinct though interrelated. Religion is one way by which people express their spirituality but it is not the only way. It is a relatively narrow aspect of spirituality. Spirituality is an overarching construct which is shaped by culture. Spirituality has three aspects to it: intrapersonal (to find meaning in life), interpersonal (to build relationship) and natural (to connect to nature and the environment). Spirituality is expressed through beliefs, values, traditions, practices, experiences and behaviours.

Similarly, religion is one's relationship with God or a deity and also includes, customs, beliefs related to afterlife and religious rituals. Spirituality underlines the expression of these cultural /religious forms. In Indian culture across classes, spirituality is understood through the lens of different religions and faiths. People have a spiritual world-view of their illness and of suffering. They derive strength from beliefs and values related to karma, the will of God, fate, punishment and reward, the power of prayer and the value of forgiveness. In Indian culture religion is perhaps the most important coping method when faced with a crisis.

Spiritual care of patients or the care provider involves valuing them as individuals and accepting their personal, values, beliefs, views and attitude towards life without any preconditions or prior judgements. It is akin to unconditional love and accepting each other as we are. It's the patient who defines the territory of spiritual care and not the carer. What is important is to recognise the potential of spiritual or religious dimension to heal whole person, body, mind and spirit. Sometimes patient's spiritual and religious needs are openly expressed, while at other time they are not expressed but have to be sensed.

CanSupport organises training workshops for counsellors on the spiritual and religious aspects of care of the patient. They must comprehend the various dimensions of spirituality, the training tools and methods to be used. Case studies and patient's narratives are discussed and are supplemented with training in the field. In order to get a deeper understanding and a wider exposure leader of different faiths and religions are also invited to interactions. CanSupport also undertakes workshops on meditation techniques.

The starting point is to hold workshops on self-awareness so that counsellors can explore their own beliefs and prejudices they hold as well as their own un-resolved issues which might get in the way of constructive work with the patient. Counsellors should get to know themselves better through such self-awareness workshops, so that they become compassionate and more accepting of the beliefs of the patient. It also makes them more comfortable around distress and strong emotions.

CanSupport's approach to counselling is culturally sensitive and patient – centred. It is responsive to the patient's preferences, needs and values and seeks to involve patients' in the process. Such an approach is always respectful. The exploration and understanding of the patient's spiritual /existential needs is an essential component of our counselling as each individual is unique. However, the following questions, which reflect their spiritual concerns are fairly common:

Why me?
What is the meaning of life and death?
Why is there pain and suffering?
Is there an afterlife?
Why has God made me suffer so much?
Is my illness a punishment for my Karma?
What can I do to make my peace with God?
Will I see God?
Does this mean I am very bad?
What is my accomplishment in life?
What will happen to me after I die?
Will I be remembered?
Will I be missed?

There are no direct answers to these questions neither should we pretend that we have them. Spiritual care is less about imparting knowledge of theology, philosophy or ritual practices, but more about the ability to be genuinely present for the patient, listening intently and not challenging the questions and doubts that are raised. It is about communicating unconditional positive regard and empathy, and creating a safe and caring environment.

In palliative care settings in India, it is usually the family and health provider who care for patient's spiritual needs. Compassionately addressing these issues increases comfort and meaning, both during the course of the illness and at the dying stage. When spiritual needs are addressed, healing takes place.

H. GRIEF AND BEREAVEMENT

CanSupport team visits the family after the death of the patient though grief counselling starts much earlier as family members experience anticipatory grief even before the death of a loved one.

The visit is planned when prayers are being performed by the family according to their religious beliefs.

As the team has played an important role in the care of the patient, the family wants to share with the team about how their loved one died. They share words that the patient spoke in the last moments and what he ate or drank. While sharing they cry. The counsellor assures them that expressing their grief by crying is normal and that it will take time to overcome their grief.

Greif

Grief I have learnt is really just love. It's all the love you want to give, but cannot. All that unspent love gathers up in the corners of your eyes, the lump in your throat and in that hollow part of your chest. Grief is just love with no place to go.(Jamie Anderson).

Grief is a normal way of reacting to loss. Grief may be felt in response to a physical loss (for example a death) or in response to symbolic or social losses (for example a divorce or a job loss) Bereavement is the period after a loss, is experienced during which grief is experienced and mourning occurs. Loss is a state of being without or the absence of someone or something to which the person is attached or values.

The passing away of a loved one is the most common way we think of loss and grief but many other significant changes in one's life can involve them too. Everyone experience loss & grief at the same time. The more significant the loss, the more intense the grief is likely to be.

EXPRESSIONS OF GRIEF

Grief is expressed physically, emotional, socially and spiritually.

1. Physical expression of grief often include headache, loss of appetite, difficulty in sleeping, weakness, fatigue, nausea, aches, pains etc.
2. Emotional expression of grief include sadness and yearning. Feelings of worry,

anxiety frustration, anger, crying, numbness are also normal.
3. Social expression of grief may include feelings of being detached from others, isolate oneself from social contact and behaving in ways that are not normal for you.
4. Spiritual expression of Grief may include questioning the reason for your loss, the purpose of pain and suffering, the purpose of life and the meaning of death.

FACTORS INFLUENCING GRIEF

1. Relationship with the person who died.
2. The circumstances surrounding their death.
3. Coping Strategies of the person and how emotional distress has been managed in the past.
4. Available support network.

TYPES OF GRIEF

Simple grief

Normal grief is perfectly natural and necessary and is the usual way in which people respond to a personally painful or traumatic situation. Everyone experiences grief in their own way. There are some temporary changes that occur when responding to loss in the days, weeks or months after the death of a loved one.

These are:

- Tears, crying
- Sleep pattern changes
- Lack of energy
- Loss of appetite such as not feeling like eating or consuming too much
- Withdrawal from social interaction and relationship
- Difficulty in concentrating on work
- Questioning spiritual or religious beliefs
- Feelings of anger, guilt, loneliness, emptiness, sadness etc., but still occasionally experiencing moments of joy

Everyone grieves a loss in their unique way and there is no definite time period for grief. Most grievers experience some of these reactions profoundly in the days /weeks following a loss but gradually return to normal in the weeks/ months. You will not forget your loved ones but in time you will learn how to cope with their absence.

ANTICIPATORY GRIEF

Anticipatory grief is the normal mourning that occurs when a patient or family is expecting a death. Anticipatory grief has many of the same symptoms as those experienced after a death has occurred. It includes all of the thinking, feeling, cultural and social reactions to an expected death that are felt by the patient and family.

Anticipatory grief could include depression, concern for the dying person, preparing for their death and adjusting to changes caused by death.

Anticipatory grief gives the family more time to slowly get used to the reality of loss. During this period people are able to complete unfinished business with the dying person. For example, saying" goodbye" "I love you "or" I forgive you".

COMPLEX GRIEF

The sadness of losing someone you love never goes away completely, but it should not remain forever. If the pain of the loss is so constant and severe that it affects your life, you may be suffering from complex grief. Complex grief is like being stuck in an intense state of mourning. One may have a problem to accept the death long after it has occurred or be so preoccupied with the person who died that it disrupts your daily routine and affects your relationships.

Indicators of complex grief includes

1. Intense longing and yearning for the deceased loved one.
2. Intrusive thoughts or images of the loved one.
3. Denial of the death or sense of disbelief.
4. Imagining that the loved one is alive.
5. Searching for the deceased loved one in familiar places.
6. Avoiding things that remind you of the loved one.
7. Extreme anger over your loss.
8. Feeling that life is empty or meaningless.

If death was sudden or extremely stressful or disturbing, complex grief can manifest as psychological trauma. You may experience feel helpless and struggle with upsetting emotions, memories and anxieties that won't go away. You may have been traumatized. But rest assured that with the right guidance you can move on with life.

THE TASK OF GRIEF

1. **Accept reality of the loss** – When you are told that your loved one has died it may be hard for you to accept it emotionally. For weeks or months after the death you may reach for the telephone or even dial the number to call your loved one only to realize he or she is gone. It is then that you have to remind yourself of your loss and accept that your loved one is gone. However even after adjusting to life without your loved one, you may have a new surge of disbelief. Remember accepting the loss does not mean letting go.

2. **Experience the pain of grief –** A question often asked is: How long does normal grief last? The answer is different for everyone as every situation is not the same. It can take several years to establish a new sense of normalcy. But life does go on. The process of grieving can help you restore harmony and balance to your life but do not rush the process.

3. **Adjust to life without your loved one** - Every day will be very unpleasant without your loved one. He or she is not there to go with you for shopping, for religious functions or any family celebration. The process of adjusting may go on for a lifetime.

4. **Find ways to Remember-** Children can experience grief and loss from a very young age. They have their own ways of grieving. It is important to recognize that children have feelings of grief and to help them express those feelings. At first it may be difficult to live without your loved one but as time goes on your life will continue to evolve, just as you do. This simply means that as time goes on you will be choosing memories, rituals and other ways of remembering your loved one.

GRIEF AND CHILDREN

It is difficult to talk to a child about death, we have to be honest with the child and help them to understand what has happened. They ask where the dead person has gone, and sometimes may feel they or anything they did, to be the cause of death of their loved one.

How to tell the child

1. We have to tell the truth in a simple and direct way.
2. We have to use concrete words that children understand for example say " died " rather than passed away.

3. We can help the child by using pictures, story books, toys to explain what has happened and how they feel.
4. Explore with children the meaning they make of the death. This may include spiritual and cultural beliefs.
5. We have to be prepared for their repeated questions. Be clear and honest in your response.

Children's reactions to loss and grief

Like adults children are also affected by loss and experience grief. Common grief reactions in children may include.

1. Grieving in doses for example crying one minute then playing the next.
2. Children act out their feelings rather than talking.
3. Changes in eating, sleeping and behaviour patterns for e.g., Children may think if they will close their eyes, they may never wake up again.
4. Wanting to sleep in bed with an adult.

BEREAVED CHILDREN

This is no doubt that the death of a person close to the child can be devastating for them. When a parent dies, the world suddenly becomes an unsafe place, in which loved ones can disappear forever. Children's understanding of death is limited by their level of cognitive development and may be even distorted. Consequently, children can experience anger, grief, fear, denial abandonment, loneliness etc. Some of the general signs are given below: -

PHYSICAL

- Sleep disturbance.
- Outburst of anger.
- Difficulty in concentration.
- Confusion.
- Hyper vigilance.

EMOTIONAL

- Loss of capacity to love.
- Sad and depressed.
- Guilt and anger.
- Insecurity.
- School dysfunction.

- Fear that surviving parent might die.
- Personal death awareness.

SOCIAL
- Withdrawal.
- Lack of interest in social activities.
- Feelings of detachment from others.

DYNAMIC OF THE SIBLINGS

When there is a very sick child in the family, often the focus is on the child who is sick, and siblings can be left out. Children in these families are often bereaved, long before they ever experience actual death. Parents are also going through anticipatory grief.

Seeing the reality in the family, healthy children bottle up their feelings and say that they are fine when they are not. This often results in feelings of resentment, jealousy, fear and deprivation of childhood. Children at an age above eight or nine years are inclined to mask their emotions and their inner life becomes disjointed and as a result, these children lack spontaneity.

At an early stage, professionals can in a non-threatening way remind the parents of the emotional needs of their healthy children. They can provide opportunities for them to express, how the illness has affected them, what can be done to improve the situation, etc.

HELPING FAMILY MEMBERS SHARE THEIR GRIEF

1. The primary goals of helping the bereaved is to facilitate communication among different family members. Communication often has been disrupted by the self-protective reactions of each family member. With the help and support of counsellors, family members are often able to talk together, and openly talk about death for the first time, and to share their feelings and memories about the loss.
2. It would be very helpful for children to see the bonding that takes place among family members as they share their grief.
3. It also helps all the family members to accept and understand their feelings of sadness, rather than avoid or deny them in a way, that can lead to a change in behaviour.

In assessing the family, it is important to keep in mind family history. In particular, how they have dealt with death, sickness and bereavement in the past. In family sessions,

members are encouraged to think about the different ways in which each is coping with their feelings about the loss. The goal of the process is to help with coping as well as to allow for differences in coping styles. Openly acknowledging differences among family members, reduces the level of tension, and make it less necessary to put up a front in order to keep true feelings inside. Family members can find the meeting, stimulating and can do their grief work in a constructive way. It helps children in the family learn more about death and receive permission to grieve. Children are likely to respond in the way in which their parents coped up with the loss.

HOW TO HELP GRIEVING CHILDREN

Children who have lost a loved one should never be left alone. They also miss the person who has died. Always remember children have short attention spans. They need to get involved in the whole process. When the prayer meetings are going on they can be asked to serve water or food to the family members who attend. They can help put flowers on the photo and can be told that their loved one is safe and not in pain any more.

Help them to make a photo album or a collage by colouring the pictures and put them on the wall in their favourite place where they can see them.
It is also normal if the child does not want to talk or share anything. At that time just be with the child and hold the child. Someone whom child loves and trusts should sleep with them. Go out for walks and play outdoor games with them. Tell them to plant a tree in the name of the loved one and encourage them to water it every day and see it grow. Slowly the child will come back to his normal self and slowly will start concentrating on their daily routine

CONCLUSION

From our experience it is very clear that successful recovery in children takes place, when: -

1. A secure relationship exists with parents prior to the loss.
2. Children are given clear and age-appropriate facts about illness and death.
3. They have an opportunity to participate in family grieving.
4. The comforting and supporting presence of a parent is available following death.
5. Grieving children are given some control within the relationship right from the start.
6. A trusting and secure environment is created.

7. Non-verbal communications are recognized and responded to.
8. There is an ability to accept the negative feelings of children.

Bereavement

Bereavement refers to the phase of mourning which one experiences after the death of a family member, loved one or close friend.

There are many models to explain grief and bereavement. One of the earliest models was given by Elizabeth Kubler- Ross. A well - known Swiss psychiatrist who identifies five stages of grief. Based on her findings she identified the 5 stages of Grief

1. **Denial -** Avoidance, confusion, shock, fear (This isn't happening to me.)
2. **Anger -** frustration and anxiety (Why is this happening to me?)
3. **Bargaining** - (I promise I will be a better person if….)
4. **Depression -** Struggling to find meaning, reaching out to others telling one's story (I don't care anymore.)
5. **Acceptance** - Exploring options, new plan for moving on. (I am ready for whatever comes)

There are some more contemporary models of grief and bereavement which are based on empirical findings across the cultures. They being

Continuing Bonds Model and Dual Process Model

GOALS OF BEREAVEMENT COUNSELLING

1. To act as emotional first aid.
2. To strengthen a bereaved person's coping skills.
3. To normalize grief.
4. To promote healthy grieving.
5. To provide support to those with special needs and those at risk.
6. To provide specialist help when grieving is complicated.
7. To maintain physical health and fitness which is often neglected.

POINTS TO REMEMBER DURING GRIEF COUNSELLING

1. Everyone experiences grief differently and there is no single way to help persons suffering from grief.

1. ACT AS A COMPANION - We should not impose our own thoughts and feelings on

people who are grieving. We need to first understand what they need. Our role is to offer companionship, a shoulder to cry on and emotional validation.

To end this:

1. Don't tell but rather listen
2. Constantly reinforce that their response is normal and natural.
3. Encourage them to use their own skill to cope with grief. To use their ability to express their feelings
4. Help them recognise and understand their feelings.
5. Encourage them to develop a schedule that allows them to manage their daily tasks.
6. Our job is to be present there.

2. VALIDATE FEELINGS - It is important to make it clear that we understand the person's feelings. Be sure that they know that such feelings are natural and people experience grief differently.

Those who experience instrumental grief focus on problem solving and try to control emotional responses. For example, in instrumental grief the bereaved person's grief may start to clean up around the house, go to the gym or play instruments

3. ASK OPEN QUESTIONS - Don't ask questions that require a "yes and no" response. Ask questions that encourage them to think about their feelings and sharing them.

- Do not ask why questions. These make it seem as if you do not understand or support their feelings.
- Always ask open ended questions. You may make a statement that initiates dialogue for e.g. "I understand it's a hard and difficult time for you," and follow up with "Please feel free to share your feelings with me".

4. PARAPHRASE RESPONSES - When they are sharing their problems give a short summary of what you think they have told you. This will assure them that you are listening actively and prompt them to share with you what is bothering them the most.

- If they tell you I cannot concentrate on my work, I feel tired, I can't sleep properly I am getting more nervous and depressed and not taking meals at the proper time - you can explain that it is your grief that is causing disruption in your daily routine.

5. REFLECT THEIR FEELINGS - When we reflect their feelings it means we have understood their emotions. .

6. REFRAIN FROM UNSUPPORTIVE BEHAVIOUR - We should not do things which are non -supportive and should avoid imposing our own solutions on them.

Do not be in a hurry
Do not watch the clock.
Do not take notes.
Do not impose your own ideas or feelings on them.
Don't give advice or ask too many questions.
Allow silence. Do not respond quickly.
Do not change the subject/topic.

7. MAINTAIN EYE CONTACT – It is very important. It shows that you are interested and engaged in what they are saying. Your eye contact must be respectful and polite. Avoid staring at the person. Maintain eye contact with short breaks when family members are not in a position to look at you because their eyes are filled with tears and emotions.

8. KEEP YOUR BODY POSTURE OPEN AND RELAXED – Sitting with your legs and arms crossed may suggest that you are closed off and not inviting conversation. Sit straight with an open posture. You should be relaxed and should be able to convey emotional support. You should face the grieving person and lean forward to indicate that you are engaged with them. Sit on the same level as the person you are talking to. This will help build open communication.

9. TALK LIKE YOU CARE - Talk with them naturally. Your tone of voice should be soft. This will show that you are listening to them with respect. Don't interrupt them or rush to answer them. It is ok to leave periods of silence. This allows them to reflect upon their feelings.

How do you help a person who is grieving after the death of a loved one?

Someone who has lost a loved one needs to be addressed with care and there are a few basic points the counsellor needs to keep in mind while providing bereavement counselling.

Ten such points are listed below:

1) To help a person grieving over the death of a loved one, you make them actualize their loss. When an individual loses their loved ones, even though there may have been some advance warning of the death, there is always a sense of unreality / a sense that it did not really happen. Therefore, the first task is to come to a more complete awareness that the loss has actually occurred; the person is dead and will not return. Survivors must accept this reality so that they can deal with the emotional impact of the loss.

Now the question is how do we help them to actualize the loss?

The best way is to keep the survivor talking about the loss. The counsellor can encourage this by asking the following questions:

- Where did the death occur?
- How did it happen?
- How did you come to know?
- What was the funeral like?

All these questions are geared up to keep the person talking specifically about the circumstances surrounding the death. Many people need to go over it again and again, reliving the events of the loss before they can actually come to full awareness. The counsellor should be a good listener and should continue to encourage the person to talk about their loss. Very often people ask questions or make statements which relate to a specific feeling as the examples below show.

Examples:

WORDS	FEELINGS
Not me	Denial
Why me?	Fear
It is not fair	Anger
No one understands	Depression
May be, but…	Bargaining
Yes, now…	Hope
I am okay	Acceptance
Goodbye	Release

2) Help the survivor identify and express feelings

Very often, people have feelings of unpleasantness and the survivor may not recognize these feelings or they might not be felt to the degree they need to be in order to bring about an effective resolution. Also, many survivors have difficulty with one or more of the following emotions: anger, anxiety, guilt and helplessness.

MANAGING ANGER

Many people do not admit to being angry when asked directly if they are, but one technique that may be beneficial is to ask a question such as, "What do you miss about them?" the person is likely to respond with a list that often brings on sadness and tears. After a short while, ask another question, "What do you miss about them?" The person may say something like this; "I never thought about it that way, but now that you mention it, I don't miss his untidy room" and there may be many more such things. This is when the person begins to acknowledge some of their more negative feelings. It is important not to leave them before they find a balance between the negative and the positive feelings they have for the deceased. The counsellor plays an important role in achieving this. In some cases, holding negative feelings may be a way of avoiding sadness. Admitting positive feelings is a necessary part of achieving an adequate and healthy resolution of one's grief.

MANAGING GUILT

There are a number of things that can cause guilt after a loss. For example, the survivor can feel guilty because they did not provide medical care or did not allow an operation, or did not consult the doctor sooner etc. Whatever the reason may be, most of this guilt is irrational and centres on the circumstances of the death. The counsellor can help with this irrational thinking by asking the question, "What are the things you have done for them?" It is also possible that there may be some real guilt that the person is experiencing and this is much more difficult to handle but must be addressed.

MANAGING ANXIETY AND HELPLESSNESS

People left behind after death often feel very anxious and fearful. Much of this anxiety stems from feelings of helplessness; a feeling that they cannot get along without their mate or will not be able to survive on their own. The counsellor's aim is to help them to recognize the way in which they managed on their own before the loss. This will help give their feelings of anxiety and helplessness some sort of perspective.

A second source of anxiety comes from increased personal awareness of death. This is something all of us have, but usually this awareness exists at a very low level. However, with the loss of a significant other, there is usually a heightened awareness

of our own mortality, which causes existential anxiety. The counsellor must address this issue and talk about fear and apprehension regarding the person's own death.

Talking to the counsellor may help the bereaved to feel a sense of relief as they unburden their concerns and explore their options.

MANAGING SADNESS

There are some occasions when sadness and crying need to be encouraged by the counsellor. Crying alone is not enough, the bereaved needs helps in identifying the meaning of their tears.

3) Assist the living to live without the deceased

This principle involved helping people accommodate the loss by facilitating their ability to live without the deceased and to take decisions independently. They need to recognize their own life skills. To help the survivor, the counsellor can use a problem-solving approach that identifies the problem that the survivor faces and how it can be solved. The deceased may have played a specific role and this often causes problems after the loss of a spouse. The counsellor can help the person learn effective coping and decision-making skills so the individual is able to take over the role performed by the deceased person and in doing can reduce emotional distress.

4) Facilitate emotional withdrawal from the deceased

This principle helps the survivor in time to form a new relationship. Some people need help in building a relationship while other's do not. Here the counsellor's job is to help the person realize that although the lost person can never be replaced, it is alright to try and fill the void with a new relationship.

5) Provide time to grief

Grieving requires time and the process has to be gradual. The counsellor can help explain this to the family. The counsellor too needs to see the intervention role as one that may, out of necessity stretch over a period of time though the actual contact may not be that frequent.

6) Interpret normal behaviour

Another principle is understanding and interpretation grieving behaviour. After a significant loss, many people have the feeling that they are going crazy. This happens because they are often distracted and experience things that are not normally part of

their lives. If the counsellor has a clear understanding of what grieving behaviour is, then he or she can give the bereaved some reassurance about the normality of their new experiences.

7) Allow for individual differences

There are a wide range of behavioural responses to grieving; and it is sometimes difficult for families to understand this. The counsellor can help individuals realise that each one has the freedom to grieve in their own way.

8) Provide continuing support

Good grief counselling requires continuing support. Counsellors can make themselves available to the survivor and family over the most critical periods, at least for the first year following death. Another good way is to offer continuing support through group participation. There are special groups for those who have lost spouses, children, parents, etc. Counsellors can refer to or lead such support groups and encourage their use.

9) Examine defences and coping styles

This means helping survivors to examine their particular differences and coping styles. This can be accomplished after trust develops between the person being counselled and the counsellor; when they are more willing to discuss their behaviour. The counsellor can highlight coping styles and help them to evaluate their effectiveness. Then, together they can explore other possible coping avenues that may be more effective in lowering distress and resolving problems.

10)Identify severity of grief and give referrals

For some people grief counselling or the facilitation of grief is not sufficient, and the loss or the way they are managing the loss may give rise to more distress. Some of these challenges may require special interventions and special techniques for which counsellor may not be trained. Therefore, it is important for counsellors to recognize their limitations and to know when to refer a person for further grief therapy or to a Psychologist.

I. SELF CARE FOR COUNSELORS

Palliative Care counselors need to take care of themselves. At CanSupport they are taught how to do so.

Ways to maintain self care

1.PHYSICAL SELF-CARE

We need to take care of our body if we want it to run efficiently as there is a strong connection between body and mind. When we care for our bodies, we feel better and can think in a better way.

Physical self-care includes what we are eating, how much sleep we are getting, how much activity we are doing, and how well we are caring for all other physical needs. Attending appointments, taking medication as prescribed, and managing our health are all part of good physical self-care.

When it comes to physical self-care, you can ask yourself the following questions to assess whether there might be some areas you need to improve:

- Am I you getting adequate sleep?
- Is my diet fuelling my body well?
- Am I taking charge of my health?
- Am I getting enough exercise?

2.SOCIAL SELF-CARE

Socialization is key to self-care. But, often, it's hard to make time for friends and it's easy to neglect relationships when life gets busy.
Close connections are important for our well-being. The best way to cultivate and maintain close relationships is to put time and energy into building them
There isn't a set number of hours you should devote to your friends or work on your relationships. Everyone has slightly different social needs. The key is to figure out what your social needs are and to build enough time in your schedule to create an optimal social life.
To assess your social self-care, consider:

- Are you getting enough face-to-face time with your friends?
- What are you doing to nurture your relationships with friends and family?

3.EMOTIONAL SELF-CARE

The way we think and the things that are filling our minds greatly influence our psychological well-being.

Mental self-care includes doing things that keep the mind sharp, like puzzles, or learning about a subject that fascinates. Reading books or watching movies that inspire also fuels our minds.

Mental self-care involves doing things that help you stay mentally healthy. Practicing self-compassion and acceptance, for example, helps you maintain a healthier inner dialogue.

Here are a few questions to consider when you think about your mental self-care:
- Are you making enough time for activities that mentally stimulate you?
- Are you doing proactive things to help you stay mentally healthy?

4. SPIRITUAL SELF-CARE

To make your lifestyle healthier you could consider exploring your spiritual needs. Nurturing our spirit, doesn't have to involve religion. It can involve anything that helps you develop a deeper sense of meaning, understanding, or connection with the universe. Whether you enjoy meditation, attending a religious service, or praying, spiritual self-care is important.

As you consider your spiritual life, ask yourself:
- What questions do you ask yourself about your life and experience?
- Are you engaging in spiritual practices that you find fulfilling?

Counselling is a demanding job and can be stressful. It is also wonderful, consistently challenging, inspiring, and fulfilling.

This acceptance of being human encourages a healthy balanced life so here are some of the lessons it teaches:

i. **There is no shame in seeking support:**

When looking after vulnerable people a willingness to acknowledge your own needs should be encouraged - how can you expect those you care for to do this if you can't do it for yourself?

Being honest about your capabilities is also important for building trust in the therapeutic relationship, as people can sense anxiety. This is a helpful life lesson for anyone with responsibility for others, whether as a parent, carer, or professional.

ii. **Looking after yourself benefits everyone**

Caring for others in any form can take its toll on physical and mental health. So in the counselling profession, it's important to take care of yourself otherwise you won't be able to help others to your best ability. Remember, self-care is far from selfish as it benefits everyone.

Ensuring time for rest, relaxation, exercise, and recharging in our daily routine is essential.

iii. **Night is the time to let go**

Hearing people's most personal stories is an absolute privilege, but for it to be sustainable you have to develop the ability to compartmentalize or 'put away' issues. Strong boundaries around non-work time and completely 'letting go' at night are essential. A great way to manage stress at the end of work is to make a note of what you are going to do and when and then let it go. Having a strong sleep routine that supports your body and mind to wind down is also vital.

iv. **Strong boundaries make for a healthy life**

Seeing many patients, a week makes holding boundaries an essential professional skill. A counsellor who worries about every individual between sessions won't last long. Routines for note taking, planning for supervision, additional reading and reflection are all strategies that you can use to cope, and rituals for literally locking these away at the end of a session helps with the move back into personal life. You must make some separation between your caring and personal roles.

v. **You can only do your best**

Having the confidence to say 'I've done all I can' and knowing the limits of your responsibility are vital for a counsellor. In any given situation you can only do your best and once that time has gone, you must let go.

vi. **Switching off is a daily essential**

Making space for activities that recharge and refocus you brings balance to life in general. Losing yourself in creative, relaxing, or in entertaining activities must be a routine part of your life if you want to stay strong and able to focus. This means scheduling time for yourself and seeing it as of with equal importance to the work you are doing.

vii. **Value yourself as you value others**

Counsellors should believe that they are just as human and potentially vulnerable as their patients rather than that they are some superior being. They should seek to work alongside people rather than lead them.

This is underpinned by a belief in a positive human drive and unconditional positive regard for fellow humans. Not applying the same principles of care to yourself would be hypocritical.

viii. **Humans are resilient, adaptable, and essentially good**

Working with people experiencing trauma, in great distress, learning to adapt to chronic illness, feeling suicidal, working on past abuse, overwhelmed with grief but trying to cope is surprisingly inspiring & uplifting. One of the best things is seeing every day the strength and basic good in people. This makes for a great experience in what can be a difficult world. It helps us keep faith that we are part of something amazing and that we all deserve to be cared for and loved, and that includes you.

A few self-care practices to reduce stress and enhance well being

1. Give your body ten minutes of mindful attention.
   Use the body scan technique to check in with each part of the body.
2. Oxygenate by taking three deep breaths.
   Breathe into your abdomen, and let the air puff out your stomach and chest.
3. Get down and boogie.
   Put on your favourite upbeat record and shake your body.

4. Self-massage.
   Take a massage so to feel refreshed.
5. Run (or walk, depending on your current physical health) for a few minutes.
   Or go up and down the stairs three times.
6. Narrow your food choices.
   Pick two healthy breakfasts, lunches, and dinners and rotate for the week.
7. Activate your self-soothing system.
   Stroke your arm, or if that feels too weird, moisturize.
8. Make one small change to your diet for the week.
   Drink an extra glass of water each day, or have an extra portion of veggies each meal.
9. Give your body a treat.
   Pick something from your wardrobe that feels great next to your skin.
10. Be still.
    Sit somewhere green, and be quiet for a few minutes.
11. Get fifteen minutes of sun.
    Especially if you're in a cold climate.
12. Inhale an upbeat smell.
    Try peppermint to suppress food cravings and boost mood and motivation.
13. Have a good laugh.
    Read a couple of comic strips that you enjoy.
14. Take a quick nap.
    Ten to twenty minutes can reduce your sleep debt and leave you ready for action.

Self-care is considered to be a continuous learning process and an individual practise of health management. So, incorporating healthy self-care practises into daily life can have lasting benefits. Taking care of body, mind, and soul is important for enhancing self- care. With a little bit of attention to our own self-care the fog will lift and we will feel more connected to ourselves and the world around us. We shall feel delighted by small pleasures and nothing will seem as difficult as it was before.

J. APPENDIX (CASE STUDIES)

All names have been changed to protect privacy

CASE STUDIES OF PATIENTS AND THEIR FAMILIES

CASE STUDY I (TOTAL PAIN MANAGEMENT)

Patients History

Ajeet (name changed) was a 35-year-old male patient with cancer of buccal mucosa (a cancer of the mouth) He had a wife and twin children, 4 years of age. He was diagnosed with this disease in 2007. He had his surgery and had a part of his jaw removed and had plastic surgery done. After a year he had severe pain in his pelvic area and during a follow-up visit his doctor announced that his disease was now in his pelvic area and one leg. He was given chemotherapy and radiotherapy.

Patients concerns

1. Severe pain despite morphine pump and SOS morphine.
2. He could only walk with the use of a stick.
3. As the only earning member in his family he was worried about his wife and small children.
4. He can no longer drive his scooter for his business.
5. His work which was supplying steel utensils to shopkeepers from the whole sale market, had to be curtailed.
6. A self-made man, he did not want to take help from others.
7. As he was an introvert, communicating with him was also difficult.

Wife's concerns

1. She felt cheated because soon after her marriage her husband had gone for his surgery and she had not been told about his disease.
2. Later when she was told she already had twins.
3. His parents left the family in the lurch and they had to manage on their own.
4. She was very worried about him and the progression of his disease.
5. As a housewife she was very worried about financial issues.
6. She was worried about their children's education and future.
7. There was also a relationship problem.

Children's Issues

1. They were worried about their father's disease
2. They were trying their best not to show their feelings.
3. They could not concentrate on their studies

The team of doctor, nurse and counselor visited the patient every week. His pain was managed very well by titrating medicines.

The counselor understood his mental pain of just being the lone earner in the family. They spoke with the social worker and with the help of a donor his scooter was changed into a four-wheeler so that he could once again drive with ease. This helped him resume his work.

His wife was very worried about Ajeet's health and had no support from his family. The team spoke with her parents. They came forward and started helping the family and building a relationship with their grandchildren. The children too began to feel cared for and started studying and going to school regularly.

Relationship issues were discussed with both of them. They started caring for each other more and a strong bonding developed. Ajeet also helped his wife learn about his business. She started helping him. She expressed her concern that because of his illness and children being young it was difficult for her to leave the house for a long time. Again, with the help of our social worker a hand cart was given which was parked outside their house so that daily she could sell some decorative items and steel utensils without leaving the children. She was very satisfied and her children also started helping her. The children became very responsible and used to share everything with the team.

The patient has been with us for the last twelve years and his total pain was managed by the CanSupport team. His disease progressed but he was glad that he could see his children grow up. His wife also acquired a skill and got a job in a beauty parlor.

CASE STUDY II (FINDING WAYS TO HELP DURING THE COVID- 19 LOCKDOWN)

The team enters the colony where they can see just a few cows and pigs roaming around. There was total lockdown and in the scorching heat they knock on the door of an elderly patient. She was Anita (name changed) a 65-year-old female with carcinoma of the ovaries that had spread to other parts of her body. She had no children and her main caregiver was her 70-year-old husband. She was unable to perform her daily chores any more. She was undergoing palliative chemotherapy from DSCI (Delhi State Cancer Institute) but due to the closure of all OPDs her treatment had stopped. Now her husband did all the household chores in addition to caring for her.

They had rented a room and were managing their finances from a meagre income.

Issues of the family

1. The couple were living all alone and had no support from relatives.
2. Because of the lockdown their tenants had suddenly left the house and their only source of income was gone.
3. They could not go to hospital for treatment.
4. They had no medicines and no ration support and were therefore very distressed about their survival.
5. The husband was home bound and he could not go out to shop or to get support

Interventions done by the team

The CanSupport team had been visiting this patient for the past one year.

The team has been giving Anita her pain medicines and other supplements. When the husband broke down and admitted that there was no food in the house, the counselor requested a family living nearby, whose mother the team had looked after, to help this family. The family immediately responded and saw this as an opportunity to help someone going through the trauma they had undergone. They offered to send cooked meals for the old couple twice a day. Arrangements were also made by the team to provide ration support. The team was buoyed by the fact that even during lockdown people were ready to help one another.

CASE STUDY III (COMPASSION AND EMPATHY)

Komal (name Changed) was a young female patient suffering from tongue cancer and unable to swallow anything orally. She was dependent on a feeding tube (Ryles tube) for her survival. She was seriously ill, was on morphine and seemed to be very, very sad. The counselor would ask how she could be of help to her, but never got a response. Once in Komal's absence, her mother-in-law disclosed that she was sad because her parents and family had abandoned her and did not visit her.

One day, with compassion and sensitivity and ensuring complete confidentiality, the counselor asked her why she was so sad. She admitted that it was because her parents didn't meet her as she married without their consent. With permission from Komal the counselor called her mother and requested her to visit her daughter as she was at the end of her life. The counselor tried her best to convince her mother but her mother continuously insisted that as far as she was concerned her daughter had already passed away a few years ago. It was obvious that her mother was badly hurt and was unable to forgive her. She said that because of Komal she had had to face lot of discrimination from society and that her younger daughters were still unmarried because Komal had ran away from her parents' house and got married. The counselor told Komal the truth that her mother was not ready to visit her. Komal had feelings of guilt, shame, repentance and anger. It was very difficult for the counselor to convince Komal that marrying someone according to one's will is not a sin. Gradually by sharing her feelings she accepted the fact that she had sought forgiveness but that it was in the hands of the other person to forgive or not. She said that in repentance she had found her solace. The counselor also discussed the need for her to forgive herself. She started appreciating the love, care, support and concern her husband had for her and that he had always stood by her. Komal's life now began to change slowly and gradually. She started doing light work at home and talked and laughed. The past no longer held her prisoner.

Komal's last wish was to visit the Balaji temple. The counsellor conveyed it to her husband who willingly fulfilled it. She was very happy when she left for the pilgrimage. She was supposed to come back after four days. The counselor called her six days later and was told that she was at peace, and wanted to rest and sleep as she was tired. That night she passed away peacefully.

CASE STUDY IV (FINDING MEANING IN LIFE)

Rita (name Changed) is a 35-year-old married female patient who has osteosarcoma of the leg. She lives with her husband and a 3-year-old son. Her in-laws stay in their village but her parents live near her house.

On their first visit the CanSupport team observed that the patient was in severe pain and was distressed because doctors had recommended an amputation of her affected leg right away. Her concerns were:

1. What will happen once an amputation is done
2. Who will take care of my child and husband?
3. How will I go out of the house without a leg?
4. I do not want to use crutches.
5. I have always prayed to God why is He punishing me?

The family too had their own concerns:

1. Will she be pain free?
2. Will the surgery cure her?
3. How will she able to walk and do her work?
4. Why is God has punishing her?
5. How will she cope?

For the team there were several issues that they needed to reflect on and deal with. Among them was - The emotional pain of the patient, her fear of surgery and her spiritual concerns.

In order to address these issues, counselor began to observe the patient and the family while the doctor focused on managing her pain and other symptoms.

On the second visit the patient and the family started sharing their fears. The doctor explained that as the cancer was localized and had not spread this was the best time to get surgery done. The counselor listened to her concerns, validated them and discussed with her that perhaps the best way to cope was to face one thing at a time and take each day as it came. After her amputation she could walk with the help of crutches and could later be fitted with an artificial leg that would help her walk and resume her normal activities.

After lots of counseling she went in for her surgery which was successful. Initially she walked with the help of crutches and did all her household work sitting on a chair. Later, she underwent chemotherapy and radiotherapy and once her cancer was considered cured, she opted for an artificial leg prosthesis. The team helped find a donor who helped her get her prosthesis made and fitted free of cost. She was able to walk again on her own.

She now began to say that God is so merciful that he has given my life back and now I will be able to take care of my child and husband.

She confided to the team that she had found a meaning in her new life. She wanted to be part of a peer support group and support and counsel patients who were suffering from a similar kind of cancer with its attendant concerns.

CASE STUDY V (MANAGING CHILDREN WHEN A PARENT IS AT THE END OF LIFE)

There was a family of three persons under the care of the CanSupport home care team. Mother, father and a daughter 5 years of age. The mother was in the last stage of cancer and the doctors said that she had only a few months to live. The father was very worried about what would happen to the daughter after his wife was gone. The mother was also very worried about who would take care of the daughter when she was gone. The father was the only earning member of the family and he had to go out to work every day.

When CanSupport first visited the patient, the family was very distressed. The issues they faced were

1. How to leave the child alone after the mother is gone?
2. How to tell the child about the mother's condition?
3. Who will take care of the child when she comes back from school?

These were very genuine concerns. The team sat with the child's parents and listened to their concerns. They explored if there were any relatives staying nearby. A brother of the father was staying a kilometer away from the house and he had a child as old as their daughter. The counsellor explored the possibility that the father speaks with his brother about shifting closer to his house or offer that he and his family could shift closer to them.

The father spoke with his brother who instantly agreed with the possibility. His wife was very fond of her husband's niece and said that it would be nice for her son to have company. They both were studying in the same school therefore the problem of the child coming back alone would also be sorted.

The family shifted next to the brother's house. On asking the father to speak to the daughter about her mother's illness by the counsellor, the father started discussing her mother's condition with the child. He told her that her mother was getting sicker by the day, and that the doctors were doing their best but that she was not getting any better. The child started getting involved in taking care of her mother by giving her water and chatting with her whenever she felt up to it. She started going with her aunt's son to school which was a great relief to her mother.

After few days the mother passed away peacefully. The child was told to put Ganga Jal in her mouth. The child felt involved. She cried after her mother's death but because she was not left alone and was emotionally and socially supported, she was able to cope much better. The father put up a beautiful smiling face of his wife's photograph in their room. The child before leaving for school would stop and join her hands in front of the photo. She would reassure her mother that she would return soon and asked her to be happy with God.

Despite his grief at losing his wife the father thanked the CanSupport team for the support they had provided him and his daughter.

CASE STUDY VI (SPIRITUALITY)

Rajan (name changed) was a 57-year-old male patient who had cancer of the head and neck region. He was diagnosed with cancer 15 years ago. He had his treatment done and was considered cured. At that time, he had two young children a son and a daughter. After 15 years he had a recurrence of his cancer. Rajan underwent chemotherapy and radiotherapy. However, this time cancer had metastasised and he lost all hope of getting cured.

Rajan had been registered with the home care team when he was first diagnosed with cancer 15 year ago and he again registered with them.

Rajan was very depressed and angry. This was understandable as he wanted to live. His anger was directed at God as he felt that he had prayed regularly and had always followed a healthy life style. He was also angry because he had a huge disfiguring wound on his cheek which made it difficult for him to eat.

His anger was also directed at his wife and two children because they used to force him to take medicines and food.

The CanSupport team used to visit him weekly. The nurse would bandage his wound so that no flies could infect it and the foul smell disappeared.

The counsellor listened to him patiently and tried to help him handle his anger issues. He confided that he could not sleep as the question "Why me" kept him awake. He would cry and feel better, but said he did not want to live anymore like this. The counsellor screened him for depression he was started on mild antidepressants. In two weeks- time he felt better but his wound had spread and he now found it difficult to swallow. The team asked him to allow them to insert a feeding tube (Ryle's tube) as the family too was feeling very distressed.

He refused to allow Ryle's tube insertion. Instead he requested his family members and the team to request his priest to perform a three-day puja while he fasted. He said he would take only sips of water and that after three days he would decide whether God wanted him to use a feeding tube or not. Understandably, the family was alarmed by his decision.

The counsellor spoke to Rajan about their concerns. He was very calm and adamant that he would feel peaceful after the puja and fasting. Fasting in his religion, he believed was a sacred act. The counsellor explained his stance to the family and argued that he had a right to live the way he wanted to. It was agreed that after the three days were over they would go according to his decision.

The family made arrangements for the puja. Rajan became very peaceful during these three days during which the team came regularly. On the third day he blessed his family and the team and died peacefully that night.

The family felt good that they had fulfilled his last wish and that he had died peacefully after the puja was over. They believed that he was now with God and in no pain.

CASE STUDY VII (ISSUES OF LIVING WITH DIGNITY)

Neeta (name changed) was a 38-year-old female patient, married, with three children aged 14, 12 and 9. They were all school going. Her husband and mother were the main caregivers. Neeta was diagnosed with leukaemia three years ago. Her husband had a small tyre shop near his home.

Neeta was a very positive lady, but as time passed, she faced many challenges. The main issues were financial and emotional and also related to her sense of personal dignity.

The children were going to private schools and they were no longer able to pay their fees. The school authorities had started calling which depressed her. The children too were fearful that they may lose a year if the school fees are not paid.

Her husband had started losing customers because, he had to take Neeta to the hospital every week.

Neeta developed severe lymphoedema of lower limbs and became totally bedridden. This made her totally dependent on others.

Her elderly mother was cooking the family meals, sending the children to school as well as attending to Neeta after she was bedridden.

Her husband had started spending less time with the family and had stopped talking with Neeta. He was scared of losing her.

When the team visited for the first time, she was totally bedridden and was dependant on her mother for her basic needs like brushing her hair, bathing, etc. She didn't want to impose on her children because of their studies. The house was a rented house with two small rooms so there were also issues of privacy. The counsellor listened to Neeta who cried a lot as she related her story. After listening the counsellor asked her which problem troubled her the most.

She said that she felt helpless as she could no longer look after her children. She could not even cook for them. The second most pressing issue for her was her inability to manage her own needs.

The counsellor asked her if she would be willing to use a wheelchair at home. She readily agreed. In the next visit the team came with a wheelchair which had been donated by a well-wisher. The team taught her and the family how to use the wheelchair. Soon, with the help of the wheelchair she began to make meals for the family, pack the children's tiffin boxes, etc. Her smile was back on her face.

Regarding her children's school problem, the counsellor met the school authorities on her behalf and explained the problem. They were cooperative and agreed to not take fees for the present financial year and the children would be allowed to give their final exams. But after that they would have to shift to another school. The counsellor spoke with the family and children and asked them to consider getting admitted to a good government run school. They agreed and were in time admitted to a government school just walking distance from their home.

The counsellor also explored the husband's problems with him. Seeing the team working closely with the family he opened up and began to share his fears as to what would happen to them if he lost his wife. The counsellor suggested that he take it one day at a time and not lose the precious moments that he could still have with his family. The mother also agreed to provide privacy to the couple by sleeping with the children in the other room The husband's work also started to pick up and with this his stress levels also came down.

The children went to school at different times and began to divide the household work, like cleaning the house, washing the dishes and clothes with their grandmother. They also insisted their mother to sit on her wheelchair to go to the bathroom and bathe on her own.

Exercises were taught to Neeta for her lymphedema and her leg movements became better.

Neeta's mother felt that she now had spare time that she could use to help the family save money. She requested the team for a sewing machine to stitch clothes. CanSupport arranged a donor.

The family were now better placed to manage their affairs and Neeta felt that she could now die in peace.

CASE STUDY VIII (Listening helps in decision making)

Meena (name changed) was a 43-year-old female patient with breast cancer. She had two children. The son was doing his hotel management while the daughter who was very good in sports was receiving training from an institute. Her husband had a small grocery shop and the family felt at a loss when the doctors said that Meena was living on limited time.

The issues Meena and her family faced were as follows:

1. Meena knew about her diagnosis but not her prognosis.
2. The family members were at a loss as to how to tell her the prognosis.
3. Meena was very worried about her children's future.
4. She could not bear to see her husband so tense.

The doctor on CanSupport's home care team had started her on pain medication after the first visit but she got no relief. The counsellor started exploring and assessing her emotional and spiritual pain. Meena's constant refrain was "I wish God grants me another five years so that d I shall be able to see my children settled" The counsellor listened attentively and asked her to take a step at a time. First she should speak with her treating doctor about her prognosis and then sit down and plan with her family how the children would achieve their goals.

Meena picked up courage and broached the subject of her prognosis and further treatments with her doctor. The doctor explained that the treatment she was being given was not helping her. He asked if she would be willing to go on a clinical trial and take a drug which was still being researched. She asked him to give her some time to think over.

She spoke with the counsellor and asked for her advice. The counsellor suggested that she should speak with her family and then take a decision. She finally decided to take the drug saying if it works at least other patients will benefit from the results. Her confidence had improved because she now had a counsellor with whom she could share her concerns. The drug did benefit her and her symptoms were now well managed. She was able to see her children finish their studies and felt mentally at peace and able to face whatever the future held for her.

K. REFERENCES

- Panikulan A. Counselling & Palliative Care- A handbook for Counselors. CanSupport, New Delhi. 2009.
- Chaturvedi SK, Chandra PS, Simha S. Communication Skills in Palliative Care. VHAI. 2008.
- Chaturvedi SK, Chandra PS, Channabasavanna S, Beena M, Pandian R, Chandra P. Detection of anxiety and depression in cancer patients. NIMHANS J. 1994;12(2):141-4.
- Sprzer R, Williams J, Kroene K, Hornyak R, Mcmurrax J. Validity and utility of the Patient Health Questionnaire in assessment of 3000 obstetric-gynecologic patients: the PRIME-MD Patient Health Questionnaire Obstetrics-Gynecology Study. Am J Obstetr Gynecol. 2000;183:759-69.
- Spitzer RL, Kroenke K, Williams JB, Group PHQPCS, Group PHQPCS. Validation and utility of a self-report version of PRIME-MD: the PHQ primary care study. Jama. 1999;282(18):1737-44.
- Doyle, Derek; Hanks, Geoffrey; Cherny, Nathan I.; Calman, Kenneth. Oxford Textbook of Palliative Medicine, 2nd Edition.
- Kubler-Ross E; On Death and Dying. Simon &Schuster.1969.
- Santosh K Chaturvedi; Clinical Psycho-Oncology: Indian Perspectives and Research,First Edition:January 2021; 33-47.
- Hautamaki.K.et al 2007; Opening Communication with Cancer patients about Sexuality – related issues; Cancer Nursing, 30, 399-404.
- Elaine Wittenberg, Betty R. Ferrell, Joy Goldsmith, Sandra l. Ragan, Myra Glajchen, The Rev. George F. Handzo; Text book of Palliative Care Communication, Oxford University Press. 2016.
- Max Watson, Caroline Lucas, Andrew Hoy, Jo Wells; Oxford Handbook of Palliative Care Second Edition 2009.
- Jimmie C Holland, William S Breitbart, Paul B Jacobson, Marguerite S Lederberg, Mathew I Loscalzo, Ruth S Mccorkle; Psycho-Oncology, Second Edition, Oxford University Press 2010; 119-126.
- Sriram TG, Chandrashekar CR, Isaac MK, Shanmugham V. The General Health Questionnaire (GHQ). Comparison of the English version and a translated Indian version. Soc Psychiatry Psychiatr Epidemiol. 1989 Nov;24(6):317-20.

CanSupport Helpline Numbers: 011-41010539 / 91-9899011212,
Monday to Saturday - 9 am to 6 pm

Saath Saath National Palliative Care Helpline: 1800-202-7777,
Monday to Saturday - 10 am to 6 pm

Website: www.cansupport.org
Email: info@cansupport.org
Address: A-2, Gulmohar Park, (Opp Kamla Nehru College), New Delhi - 110049