RAJIV GANDHI CANCER INSTITUTE & RESEARCH CENTRE
1996

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FREQUENTLY ASKED QUESTIONS IN PALLIATIVE CARE

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CLOSE THE CARE GAP

with

"Effective Pain Management & High Quality Palliative Care"

PALLIATIVE CARE

SUPPORTIVE CARE

RESPITE CARE

HOSPICE CARE

Physical
- Caused by cancer
- Treatment related
- Co- morbid conditions

Psychological
- Anxiety
- Depression
- Past Illness Experiences
- Fear of Suffering

Spiritual
- Anger
- Loss of faith
- Difficult to find meaning
- Unknown fear

Social
- Loss of role
- Loss of social status
- Loss of job
- Worries about future
- Dependent

Total Cancer pain

We believe in comprehensive Oncology Services

RGCIRC
Ethics, Empathy & Excellence

Rajiv Gandhi Cancer Institute & Research Centre,
Niti Bagh

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01. GENERAL QUESTIONS ABOUT PALLIATIVE CARE

1. What is Palliative Care?

Palliative care is specialized medical care which is given to the patients suffering from some serious life limiting illness.

2. What is the aim of Palliative Care?

It aims to improve the quality of life of patients and families who are associated with life threatening conditions such as cancer, heart failure, chronic obstructive pulmonary disease, advanced liver or kidney disease, alzheimer's, parkinson's, motor neuron diseases, neuropathies and many more.

3. Why is "Early Pain and Palliative Care management" necessary?

Early Palliative Care delivers quality life to the patient by providing pain relief, controlling the symptom burden and providing psychological/ spiritual/emotional support.

4. What are the main causes of cancer pain?

- Infiltration by tumour itself or compression over the nerves
- Metastasis to bone or joint space
- Peripheral neuropathy causing tingling and numbness
- Degenerative changes in spine/joints – not related to cancer
- Sensitization of the nerves
- Psychological/social/spiritual burden causing pain

5. How is the pain management done?

- Counselling plus pharmacotherapy using WHO analgesic ladder approach
- Minimally invasive pain and spine interventions (MIPSI)
- Implantable systems (intrathecal / epidural pump)
- Central desensitization therapy for sensitized nervous system

6. What are the symptoms managed by Palliative Care Team?

- Pain
- Psychological, spiritual, emotional symptom burden
- Gastrointestinal symptoms like nausea, vomiting, constipation, diarrhoea

- Loss of appetite
- Swelling/lymphoedema care
- Insomnia and sleeplessness
- Anxiety and depression associated with cancer
- Cough and breathlessness
- Dry mouth
- Infections and wound care
- Ascites drainage

7. Is it just end of life care?

Palliative care is not just end of life care. End of life care or hospice care is a part of palliative care which is provided during the last few months, days or hours of life.

8. What is Respite Care?

While prioritizing the patient, carers often end up neglecting their own needs eventually ending up exhausted, drained, frustrated and depressed. Respite care is an integral part of palliative care which is given when someone else such as hospital doctor or nurse takes care of the patient instead of the primary caregivers so that the carers can have a break for themselves.

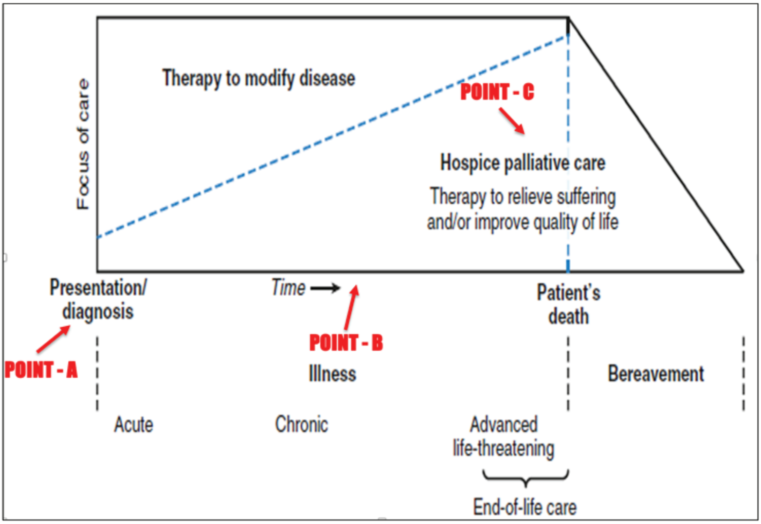
02. WHAT IS THE DIFFERENCE BETWEEN TERMS PALLIATIVE CARE, HOSPICE CARE AND END OF LIFE CARE (EOLC)?

Palliative care: It should be started at the time of diagnosis with cancer or any chronic life-limiting illness. Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with a life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment, and treatment of pain and other problems, whether physical, psychosocial, or spiritual. It offers a care process that goes beyond the physical symptoms. It uses a team approach to address suffering and support the patients and their families, starting with the diagnosis, treatment phase, hospice care, end-of-life care, and providing bereavement counselling. Palliative care is explicitly recognized under the human right to health and is provided via a patient-centric approach. It is now an integral part of the health services system under global standards.

Hospice care: This term is used when the disease, such as advanced cancer gets to the point when the treatment can no longer cure or control it. Hospice care denotes that the patient is expected to live about 6 months or less if illness runs the usual course. Goals of care here shifts from cure towards care, control, and quality of life. When the cure to serious illness is not possible, or the patient chose to not undergo disease directed treatments, it is time to label them as hospice care and counsel them to prepare for the next phase of life i.e, end of life care.

End of life Care (EOLC): It refers to health care process that is provided during the last few hours, days or months of life. It encompasses care and support for the patient’s mental and emotional needs, physical comfort, spiritual needs and practical tasks.

The graph below shows the placement and relevance of these common terms during the trajectory of cancer or a chronic life-limiting illness.



Point A: the time of diagnosis (early palliative care)—where disease-directed therapy is to be started and the counselling part is done by the palliative care team of experts.

Point B: transition from curative to palliative intent of treatment (timely palliative care)—where the symptom burden, especially in the form of severe pain, psychological difficulties, unanswered questions regarding the future, the need for prognostication, etc., is quite high.

Point C: transition from palliative intent of treatment towards hospice care or end-of-life care (preparatory palliative care)—where the role of the palliative care team is at its peak. It involves multiple lines of discussion regarding the construction of the present as well as future care plan, putting in words the anticipated events, planning to complete some unfinished tasks, explaining advanced directives along with the doctrine of double effect, and preparation for a dignified end-of-life care.

03. PAIN MANAGEMENT

1. Why is cancer pain management necessary?

Prevalence of pain in cancer patient is >50%. As the disease progresses, severity of cancer pain increases to approximately 70%. The priority is to give a good quality and pain free life.

2. How is cancer pain controlled?

- Pharmacotherapy via WHO analgesic step ladder approach gives satisfactory pain relief in majority of the cases up to terminal stages.
- Titration of the doses of analgesics is necessary as per the response.
- Refractory cancer pain cases who are not getting relieved by pharmacotherapy, need interventions for further pain relief at some point of time.
- Psychological/spiritual/social cause of pain is also necessary to be taken care through communication skills, guidance and counselling.

3. What are integrated cancer pain and palliative care services?

- Cancer pain management - Pharmacotherapy via WHO step ladder
- Cancer pain management - MIPSI (minimally invasive pain and spine interventions) done under local anaesthesia
- Cancer pain management - Opioids and other analgesics dose titration
- Cancer pain management - Advanced procedures - Intrathecal pump implantation, epidural pump implantation, spinal cord stimulator, percutaneous vertebroplasty
- Answering difficult questions related to advanced cancers
- Supportive Care - Hospital based
- Hospice Care
- Respite Care
- Management of refractory cancer pain cases
- Symptom burden management associated with any cancer
- Counselling for anxiety/depression of patient as well as family members
- End of life care (EOLC) in terminally ill

4. Name some common cancer pain management nerve blocks (MIPSI)

- **Head and neck cancer pain –** Sphenopalatine ganglion, stellate ganglion block, glossopharyngeal block
- **Mandibular or maxillary neuralgia –** Gasserian ganglion block, peripheral nerve block
- **Neck and shoulder pain –** Cervical epidural, trigger point injections, ozone injection, suprascapular nerve radiofrequency, occipital nerve block and cervical medial branch block
- **Chest and thoracic pain –** Intercostal nerve block, paravertebral, epidural, erector spinae plane block, radiofrequency ablation
- **Upper abdomen pain –** Celiac neurolysis, splanchnic radiofrequency ablation
- **Lower abdomen pain –** Superior hypogastric neurolysis, caudal epidural, transversus abdominis plane block
- **Perineal pain –** Ganglion impar block, pudendal block
- **Lower limb pain –** Transforamen epidural, selective nerve root block
- **Neuropathy pain –** Lumbar sympathetic radiofrequency (lower limb) and T2-T3 sympathetic block (upper limb)

5. Common cancer pain relief sympathetic nerve block procedures?

- **Celiac neurolysis/splanchnic radiofrequency ablation:** cancer pain arising from pancreas, gallbladder, liver, stomach, omentum, mesentry, gut till transverse colon
- **Superior hypogastric block:** pain arising from uterus, ovary, cervix, interstitial cystitis, neurogenic bladder, bladder tumour, decending colon, rectum, prostate, testis, epididymis
- **Stellate ganglion block/T2-T3 radiofrequency ablation:** pain due to brachial neuritis, lymphedema, pan brachial injury CRPS, some cancer pain of the head & neck and upper extremities
- **T2-T3 radiofrequency ablation:** cancer pain from structures like esophagus, heart, bronchi, trachea, lung, pleura and neuropathic pain involving thorax, chest wall, thoracic viscera &post herpetic neuralgia
- **Ganglion impar block:** sympathetic mediated pain of perineal region, malignancies of the pelvis or perineum, perineal neuralgia and coccydynia

6. Do Palliative Care Team treat other pain conditions apart from cancer?

Yes, other painful conditions taken care include:

- Back pain
- Disc pain
- Prolapsed intervertebral disc (PIVD)
- Neck pain
- Arthritis
- Joint pain (Shoulder, elbow, wrist, hip, knee, ankle)
- Headache/Migraine
- Nerve pain
- Neuralgia like trigeminal/glossopharyngeal neuralgia
- Phantom limb pain
- Sympathetic pain
- Diabetic neuropathy
- Complex regional pain syndrome
- Peripheral vascular disease associated pain like Buerger’s disease or Raynauds phenomenon

7. What are the other pain condition treatment options?

- Joint injections for arthritis
- Regenerative therapy for osteoarthritis [Platelet rich plasma PRP & Prolozone Dextrose therapy]
- Ozone administration - Anti-inflammatory
- Epidural (Caudal, transforamen, interlaminar) for back pain
- Vertebroplasty for spinal fractures
- Radiofrequency RFA [Pulsed RFA for prolapsed intervertebral disc causing nerve compression and Conventional RFA for sympathectomy procedure]
- Field blocks
- Peripheral nerve blocks

04. MINIMALLY INVASIVE PAIN AND SPINE INTERVENTIONS (MIPSI)

1. What is a MIPSI or pain block or nerve block?
Nerve blocks are procedures to control different types of pain. They comprise injection of medicines like local anaesthetic and steroid that block the pain arising from some specific nerves.

2. Do nerve blocks hurt?
The placement of a nerve block is associated with slightest degree of discomfort. All the procedures are done under local anaesthesia and if required minor sedation.

3. Common procedures for cancer pain management:
- Epidural
- Peripheral nerve block
- Sympathetic neurolysis
- Radiofrequency ablation
- Field blocks like Erector Spinae Plane Block (ESPB)
- Epidural/intrathecal pump implantation
- Refractory cancer pain management

4. How is a pain block or nerve block done?
A nerve block is done under local anaesthesia using real time image guidance – either C-Arm (X-Ray) or ultrasound (USG) guided.

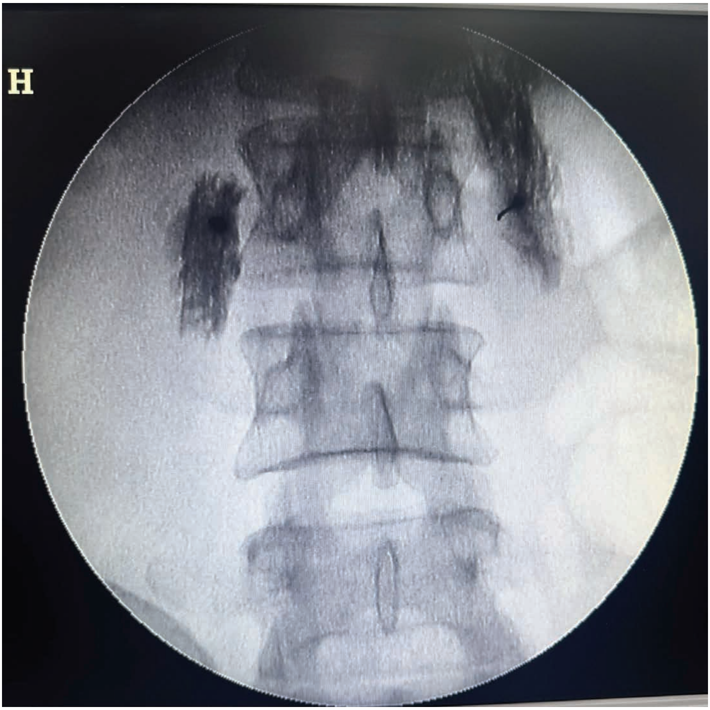
5. Drugs used in pain blocks:
- Local anaesthetic
- Steroids
- Medicated alcohol
- Medicated phenol
- Ozone gas
- Opioids

6. Cancer pain management with nerve blocks? Is it dual procedure?
- First sitting : Diagnostic block – Local anaesthetic + steroid
- Second sitting : Therapeutic block – Radiofrequency (RFA) ablation or Chemical neurolysis with alcohol/phenol

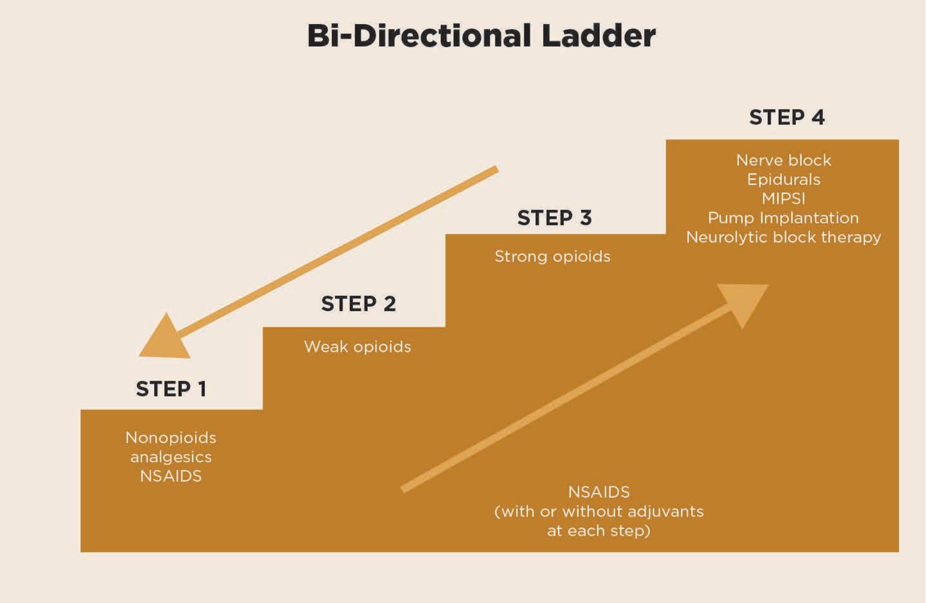
7. Do early nerve blocks/MIPSIs are required in visceral cancers?

Sympathetic nerve blocks are commonly performed at the earliest to supplement the pain control in visceral malignancies causing chronic pain. Common cancers where early interventions are required:

- Pancreas
- Stomach
- Gall bladder
- Liver
- Urinary bladder
- Ovary
- Uterus
- Rectum and anal canal
- Prostate



05. PAIN RELIEF IN PALLIATIVE CARE WHO ANALGESIC LADDER



1. What is the essential concept of WHO ladder approach?

- By the mouth
- By the ladder
- By the clock
- For the individual

ESSENTIAL CONCEPT FOR WHO APPROACH

Opioids are the mainstay of pain management in cancer patient. They are to be given as per the WHO analgesic ladder approach. Always consult a Palliative Care Specialist for the control of cancer pain so that patient can lead a quality life.

2. What is holistic approach in Palliative Care?

- Physical
- Psychological
- Emotional
- Spiritual
- Intellectual

HOLISTIC APPROACH IN PALLIATIVE CARE

Palliative care can be provided to patients in different settings, for example at patients' own homes, care homes, hospices, hospitals and day hospitals. A crucial component of palliative care is the multidisciplinary input in managing the symptoms associated with the terminal or other life-limiting illnesses. The entire emphasis in Palliative Care is on relieving and minimizing the physical, psychosocial as well as the spiritual suffering of patients and their caregivers.

3. What is the approach in Palliative Care for cancer patient?

- Honest communication
- Control of pain and associated symptoms
- Realistic hopes
- Setting goals for future
- Helping family members
- Talking and preparing about death

APPROACH IN PALLIATIVE CARE FOR CANCER PATIENT

Palliative care is an approach that addresses the person as a whole, not just their disease. A holistic care is provided to the patient and family or caregiver focusing on the physical, emotional, social, and spiritual issues which cancer patients might face during their cancer treatment experience.

4. What are the medicines used in cancer pain?

- Pain relievers like NSAIDs and paracetamol
- Weak opioids like tramadol
- Strong opioids like morphine and fentanyl
- Adjuvant medications – antineuropathic, antidepressants, bone strengthening agents, steroids, local anaesthetics, etc.

MEDICINES USED IN CANCER PATIENTS

When the patient experiences pain due to cancer, many medicines can help manage it so you feel better. Palliative Care Specialist uses the WHO analgesic step ladder approach for treatment of cancer pain. Palliative treatment can be used at the same time as other treatments intended to cure your cancer.

06. SOME COMMONLY USED PALLIATIVE CARE MEDICINES

Opioids like morphine: Apart from the pain management, it is also used for breathlessness.

Steroids: A corticosteroid that is often used to treat cancer-related pain and also used in breathlessness.

Antipsychotics: Used to treat terminal delirium, agitation and also metabolic nausea and vomiting.

Antidepressants: Used to treat mood disturbance and also in other symptoms like neuropathic pain.

Laxatives: A medication used to prevent and treat constipation induced by low motility and opioids.

Anxiolytics: Often used to calm the patient during anxiety, breathlessness, agitation and restlessness.

Anticholinergics: Often used for bladder pain, in bowel obstruction, noisy breathing / secretions and also for pain associated with smooth muscle spasm.

Prokinetics: Used as antiemetic generally for nausea and vomiting due to gastric stasis.

Hormonal agents: To improve the appetite.

07. MORPHINE

1. Why is Pain and Palliative Care referral important?

Pain management and Palliative Care referrals are important to have a comprehensive oncology care plan that has integrated palliative care services along with disease directed treatments that include surgery, chemotherapy, and radiotherapy. Palliative Care Specialist has wide experience in:-

- Diagnosing and treating different types of acute and chronic pain conditions,
- Titrating strong opioids like morphine or fentanyl,
- Doing nerve blocks,
- Providing quality life and increasing compliance to treatment,
- Handling psychological, social and spiritual burden associated with cancer,
- Handling transitioning to hospice care phase when treatment therapies are not working and disease is progressing,
- Providing good end of life care
- Working on the concept of – **LIVING WELL AND LEAVING WELL.**

2. When is morphine used?

Morphine is a strong opioid (analgesic) that is used to relieve moderate to severe pain associated with cancer progression. It is to be used under medical supervision and usually prescribed by Palliative Care Specialists. Apart from pain, it is sometimes used for controlling breathlessness and calming the patient.

3. What are the available forms of morphine?

It is usually available as tablets, capsules, injection and sometimes in suppository form. Immediate or normal release preparation gives pain relief for about 4-6 hours and controlled release or sustained release tablets can last for 12 to 24 hours.

4. What to expect while starting morphine? Can it cause addiction?

It is one of the best and cheapest treatment for controlling moderate to severe cancer pain. It is prescribed by your Palliative team Doctor and will **not** make you addict. Once started it will control your pain. Follow up visits are necessary to the Doctor so that they can assess your clinical condition and watch your pain diary through which Doctor decides whether to increase the dose of morphine or not.

It is a medicine to be taken by the clock and as per your prescription. Adjustments (increase or decrease) in the doses of morphine is a continuous process which is done during your treatment.

5. Can I stop taking morphine abruptly?

No, as with other medicines it can result in withdrawal symptoms. Do not stop taking morphine abruptly. If it is to be stopped by your Doctor, it can be done gradually or shifting to some alternative opioid medicines using the bidirectional nature of the WHO analgesic ladder.

6. Are there any side-effects of morphine?

Constipation is a very common associated effect for which laxatives are usually prescribed. Dizziness, sweating, nausea, sleepiness or vomiting can occur with some patients. Patients usually get adjusted to morphine in a few days, but if symptoms are persistent, Palliative Care team can reduce the doses or shift to an alternative opioid medicine too.

7. Can I go to work while taking morphine?

Yes, you can do self-care and be active in your activities of daily living.

8. What is the upper limit of morphine?

Morphine dose is adjusted by your Doctor as per the bidirectional WHO ladder, clinical condition and response to treatment (regression or progression of disease).

9. Do I have to stop other pain relief medications while taking morphine?

Pain in cancer is usually mixed type having a nociceptive and neuropathic component. Pain pathways usually involve a variety of receptors. Different pain medications in the WHO analgesic ladder are destined to act on different receptors and different centres of these pain pathways thus providing pain relief. Palliative Care Specialists are trained in finding the pain generators and assessing the type of pain. So, they use different types of medications including adjuvants (antineuropathic/antidepressant medications, local anaesthetics, steroids, bone strengthening agents, etc) along with morphine for controlling your pain.

10. What are the precautions while taking morphine?

- Take morphine strictly under Doctor prescription.
- Tell honestly about your medical history.
- If you are pregnant or planning to be.
- Keep medicines away from reach of children.
- Follow proper instructions of Palliative Care team and maintain your pain diary.

11. Does morphine speed up death process?

- There is “no evidence” that opioids like morphine speed up the dying process.
- In fact, researchers have suggested opioids role to treat pain and shortness of breath near the end of life that help a person live a bit longer by symptom relief.

12. Is morphine given to terminally ill cancer patients only?

Morphine can be prescribed to any cancer patient who has moderate to severe variety of pain. It can be given early in the trajectory of the disease depending upon the intensity of pain and it can be continued during hospice care as well as end of life care too as per need of the patient.

08. ANALGESIC PATCHES

1. What is an analgesic or pain medication patch, and how does it work to relieve pain?
The patch is a transdermal system that delivers a continuous dose of a pain medicine, through the skin into the bloodstream. It is for providing long-lasting pain relief, typically over hours/ days upto a week.

2. How should the patch be applied to the skin?
The patch should be applied to a clean, dry, and non-irritated area of the skin, usually on the upper body or arm. Avoid areas with excessive hair, scars, burns, or irritation. Press the patch firmly in place with the palm of your hand for 30 seconds to ensure it sticks properly.

3. What are the signs that the analgesic patch is not sticking properly?
If the edges of the patch are peeling or lifting, it's not adhering correctly. You can use medical tape or a transparent adhesive film over the edges.

4. How often should the patch be changed?
The patches should be changed based on the drug they deliver. Typically, fentanyl patches are changed every 72 hours (3 days) while buprenorphine patches are changed every 7 days. It's important to remove the old patch before applying a new one, and rotate the application site to avoid skin irritation.

5. What precautions should be taken to avoid overdose with pain patches?
Follow dosing instructions carefully, never apply more patches than prescribed by Doctor, and avoid exposing the patch to heat (such as heating pads or hot baths).

6. What should be done if the patch falls off or is accidentally removed?
If the patch falls off, dispose of it properly and apply a new one. Note the time of the new patch and continue the new cycle as prescribed by Palliative Care Specialist.

7. How should the old patch be disposed?
Fold the used patch in half so the adhesive sides stick together, and dispose of it in a way that prevents accidental exposure, such as placing it in a designated medication disposal container or flushing it down the toilet.

8. Can the patch be used with other pain medications?
Yes, the patches can be used with other pain medications, but only under the supervision of a Palliative Care team to avoid interactions or overdose.

9. What should we do if the patient's pain is not adequately controlled by the patch?
Contact the Palliative Care team for advice. They may adjust the dose, prescribe additional pain relief, or recommend other pain relieving interventions.

10. How should the patch be stored to ensure safety and effectiveness?
Store the patch at room temperature, away from heat and moisture, and out of reach of children and pets. Do not store it in the bathroom.


Figure 1


Figure 2


Figure 3


Figure 4

09. NUTRITION IN PALLIATIVE CARE

Nutrition is an essential component of palliative care, which aims to provide comfort and relief to patients with serious illnesses. Patients in palliative care may experience a range of symptoms that can affect their ability to eat, such as pain, nausea, vomiting, and fatigue. Proper nutrition can help improve quality of life and alleviate some of these symptoms.

1. He/she loves to eat, but now they are not eating. Why?

It's because of appetite loss, nausea, early satiety, taste and smell changes, constipation, dysphagia, and psychosocial factors.

a. If there is appetite loss or anorexia in that case (My patient is getting weak or losing weight day by day what can be done?)

- Minimize eating effort by preferring high energy and protein foods through small and frequent snacks throughout the day.
- High caloric liquid meals may be useful.

b. If there are taste and smell changes

- Adjust diet in accordance with new taste preferences and by avoiding foods that may evoke aversion, such as those with an intense odor (roast meat, fish).
- Prefer mildly flavored foods. Cold foods are generally less odorous.
- If the oral mucosa is not sensitive, use salt, herbs, spices, and seasonings.

c. In case of nausea and vomiting

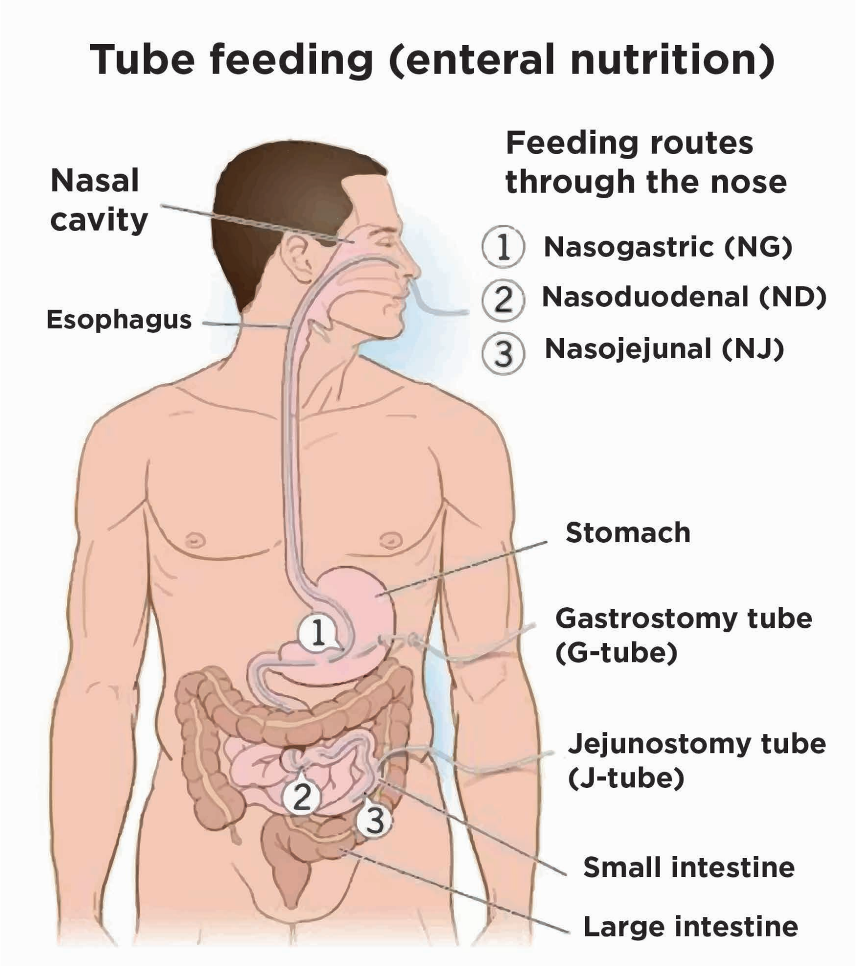
- Prefer small and frequent snacks throughout the day (crackers, biscuits) in order to avoid stomach emptying.
- Take advantage of times when the patient feels less fatigued, or between cycles of chemotherapy.

d. In case of Oral mucositis, pain

- Prefer soft, creamy, or liquid foods, and avoid hard ones that could damage the oral membrane (nuts, hard fruit, crusts, hard baked goods).
- Prefer foods at room temperature, and avoid hot dishes and beverages. Ice cold foods and fluids may be pleasant.
- Avoid extreme tastes, such as spicy and acidic foods, citrus fruits, and very salty products.

2. My patient is not able to swallow post treatment, what are the other ways of feeding?

In this case nutrition is provided through a tube that is inserted through the nose (Ryle's tube feeding) or stomach (PEG tube feeding).



3. What is parentral feeding?
This involves providing nutrition through a vein, usually through an IV line. This is typically used when the patient is unable to receive nutrition through the digestive system. It may increase the risk of infections and also it is usually avoided in patient in end of life care phase.

4. Is it necessary to feed my patient in the end of life care?
Palliative medicine encourages the patients to take feeds orally. If the patient is nearing the end of life and the goal is to provide comfort care while enteral or parenteral feeding may not be necessary.

5. Artificial hydration: what is it? When is it delivered?
It is a medical procedure that enables someone who can no longer take liquids or hydration orally.

6. Is dehydration common at the end of life? If someone at the end of life doesn't take liquids, won't they die of dehydration?
If they stop drinking, their mouth may look dry, but this does not always mean they are dehydrated. It is normal for all dying people eventually to stop eating and drinking. This is because as the body weakens and the systems start to work less well, there is lesser and lesser need for fluid.

7. My patient can have artificial hydration and nutrition?
For some conditions, this is an option. But for other conditions, and often when people are in their last days of life, there is no evidence that it helps people to live longer or improves their quality of life.

8. What is the best way to hydrate my patient?
By encouraging them to take little sips of water or putting ice chips in their mouth, by doing this they can aid in maintaining oral hygiene and hydration.

9. How much fluid or hydration is required during the end of life?
The principle of care would be to maintain adequate hydration in the dying person in the last days of life to minimize unwanted symptoms like generalized edema, breathlessness, etc.

10. RT FEEDS

1. What can be done if the patient feels discomfort or irritation from the Ryle's tube?

- Patients may experience discomfort, nasal irritation, or a sore throat from the tube. To manage this:
- Regularly check the tube's position and adjust it if needed.
- Apply lubricating jelly at the nostril entry site to reduce irritation.
- Use over-the-counter saline sprays to keep nasal passages moist.

2. What should be done if the Ryle's tube becomes dislodged?

- The tube can become dislodged due to movement or accidental pulling.
- In such cases:
- Secure the tube with medical tape or a tube holder.
- Educate family members on what to do if the tube is accidentally pulled out (do not try to reinsert it; call the healthcare provider immediately).Use mittens or restraints like boxer bandages under professional guidance.

3. How can blockage or clogging of the Ryle's tube be prevented?

- Flush the tube with warm water before and after each feeding or medication administration.
- Use liquid forms of medications when possible, or crush and dissolve solid medications properly.
- If blockage occurs, flush the tube with warm water or use ENO dissolved in 100ml water or contact the Palliative Care team for assistance.

4. How can aspiration be prevented during RT feeding?

- Aspiration (inhaling food or liquid into the lungs) can lead to pneumonia. To reduce this risk:
- Keep the patient's head elevated at least 30-45 degrees during and for 30 minutes after feeding.
- Monitor for coughing, choking, or difficulty breathing during feeds. Stop feeding if any of these occur.
- Report any signs of respiratory distress to the Palliative Care team immediately.

5. How can families manage the feeding schedule and quantities?

- Create a clear, written schedule with instructions from the Palliative Care team.
- Use alarms or reminders to stay on track with feeding times.
- Consult the healthcare team if there are concerns about the patient's ability to tolerate the feeds.
- Quantity of feed is usually less in bedbound palliative care patients due to reduced metabolism.

6. What should be done if the patient is not tolerating RT feeds well?

- Pause the feeding and reposition the patient.
- Adjustments to the feeding rate or formula may be necessary.
- Report signs like nausea, vomiting, bloating, diarrhoea, or respiratory distress to the Palliative Care team.

7. How can skin breakdown and infections around the tube be prevented?

- Inspect the skin around the tube site daily for signs of redness, swelling, or sores.
- Keep the area clean and dry, and apply barrier creams if advised.
- Rotate the position of the tape at regular intervals to reduce pressure on the same spot.
- Ensure proper hand hygiene when handling the tube.

8. How can hydration be managed when using a Ryle's tube?

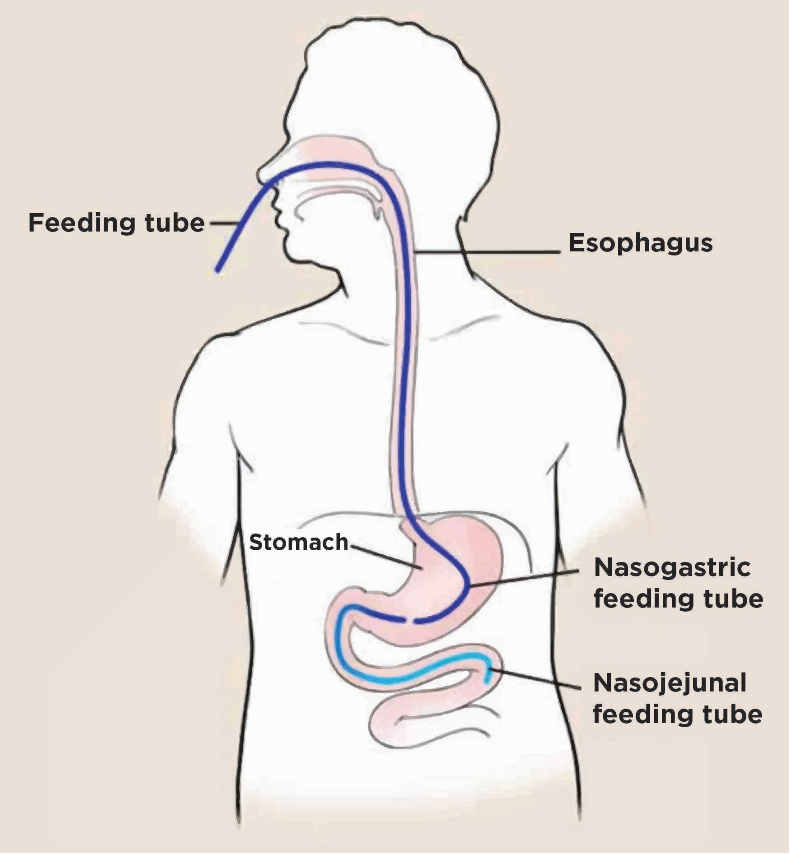
- Schedule water flushes separately from feedings.
- Monitor for signs of dehydration, such as dry mouth, dark urine, or lethargy, and report them to the Palliative Care team.

9. What types of nutrition or food can be administered through the Ryle's tube?

Liquid formulas specifically designed for tube feeding or home cooked food as recommended by the Palliative care dietician is used for nutrition.

10. What equipment-related care is required for RT feeding?

- Replacement of the tube might be required after 2-4 weeks – to be decided by the Palliative Care team.
- Clean feeding equipment, such as syringes and feeding bags, after each use and replacing them timely.



11. WOUND/BEDSORE CARE

1. How can I maintain skin integrity and care for bedsores in a bedridden patient?

- Reposition the patient every 2 hours to alleviate pressure and reduce the risk of new bedsores.
- Keep the skin clean and dry using mild soaps and moisturizers.
- Apply barrier creams or oils to protect the skin from friction.
- Use an air mattress, alpha bed, water bed, or cushions to prevent bedsores.
- Follow a wound care plan created by the Palliative Care team, which includes specific dressings and cleaning solutions.

2. How can I manage the pain and discomfort from bedsores or fungating wounds?

- Administer pain relief medication half an hour before dressing changes or wound care, as recommended.
- Use atraumatic or non-stick dressings to reduce pain during removal.
- Moisten the dressing with saline to make removal easier.
- Position the patient to relieve pressure on the sores and use soft cushioning (mattresses, pillows, foam dressings).
- Consider alternative pain management techniques such as relaxation exercises.

3. How can I manage the odor from fungating wounds?

- Apply topical metronidazole to reduce odor-causing bacteria.
- Use odor-absorbing medicated dressings as suggested by the Palliative Care team.
- Ensure the room is well-ventilated, and consider using air purifiers or odor-neutralizing agents like charcoal (as advised by Palliative Care team).
- Change dressings frequently as per recommendations and avoid using fragrant deodorants or powders.

4. How do I prevent infections or maggots in bedsores or wounds?

- Follow strict hygiene protocols, including washing hands and wearing sterile gloves when handling wounds.
- Use appropriate dressings to maintain a clean wound environment.
- Cover the wound with clean sterile gauze to prevent exposure to flies or insects.

- Watch for signs of infection (redness, warmth, swelling or pus) and report them immediately.
- Administer prescribed antibiotics or topical treatments as directed.

5. What can be done to manage drainage and leakage from the wound?

- Use absorbent dressings to handle significant drainage.
- Apply barrier creams or films to protect the surrounding skin from irritation.
- Change dressings as needed to prevent oversaturation and keep bed linens clean.
- Use underpads or waterproof mattress protectors to reduce the need for frequent linen changes.

6. How do I handle the emotional and psychological impact of caring for a loved one with bedsores?

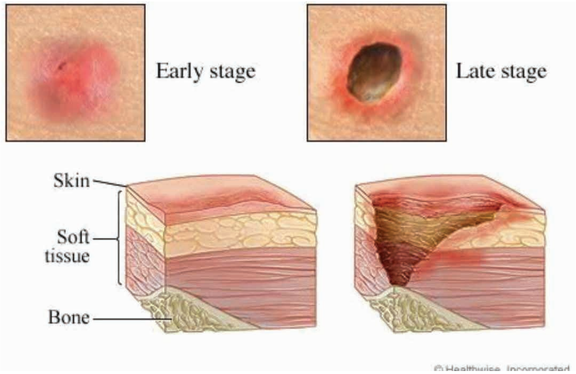
- Seek support from counsellors, social workers, or Palliative Care support groups to share feelings and experiences.
- Involve the patient in their care as much as they are comfortable with.
- Educate yourself and other family members on wound care to build confidence.
- Take breaks and practice self-care to avoid caregiver burnout and fatigue.

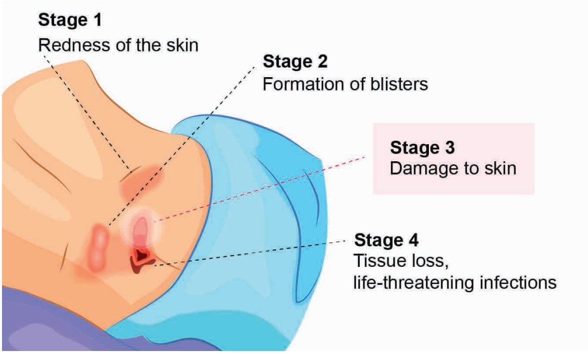
7. How can I prevent social isolation in patients with odorous wounds?

- Encourage regular social interaction through visits, phone calls, or video chats.
- Address concerns about odor openly and reassure the patient that steps are being taken to manage it.
- Engage the patient in some enjoyable activities, even if they are limited to the bedside.

8. How can I better understand and follow wound care instructions?

- Request clear, step-by-step instructions from the Palliative Care team and ask for hands-on demonstrations where ever necessary.
- Keep a written care plan and checklist to ensure all steps are followed correctly.
- Don’t hesitate to ask questions or seek additional training if unsure about any aspect of wound care.


Early stage
Late stage
Skin
Soft tissue
Bone
© Healthwise, Incorporated


Stage 1
Redness of the skin
Stage 2
Formation of blisters
Stage 3
Damage to skin
Stage 4
Tissue loss,
life-threatening infections

12. PICC LINE CARE

1. How can I prevent infection at the PICC line site?

- Monitor the site daily for redness, warmth, swelling, or discharge.
- Keep the area clean and dry, follow strict hand hygiene.

2. How often should the PICC line dressing be changed?

Change the dressing every 7 days or sooner if it becomes wet, loose, or dirty, following sterile technique and Palliative Care team guidelines.

3. What should I do if the PICC line becomes dislodged?

- Secure the PICC line with an adhesive strip or securement device.
- If dislodged, cover the area with a sterile dressing, apply gentle pressure if there's bleeding, and contact the Palliative Care team immediately.

4. How can I prevent clogging or occlusion of the PICC line?

- Flush the PICC line regularly with saline as instructed.
- If the line is difficult to flush, do not force it; contact the Palliative Care team for assistance.

5. What should I do if the patient experiences pain or discomfort at the PICC line site?

- Mild discomfort may be normal initially, but persistent or worsening pain should be reported.
- Ensure the dressing is not too tight and avoid unnecessary pressure on the area.

6. What should I do if the arm or hand swells near the PICC line?

Swelling may indicate a blood clot or other complications. Contact the Palliative Care team immediately for further evaluation. A USG Color Doppler, blood tests/cultures might be required now.

7. How can I keep the PICC line dry during bathing?

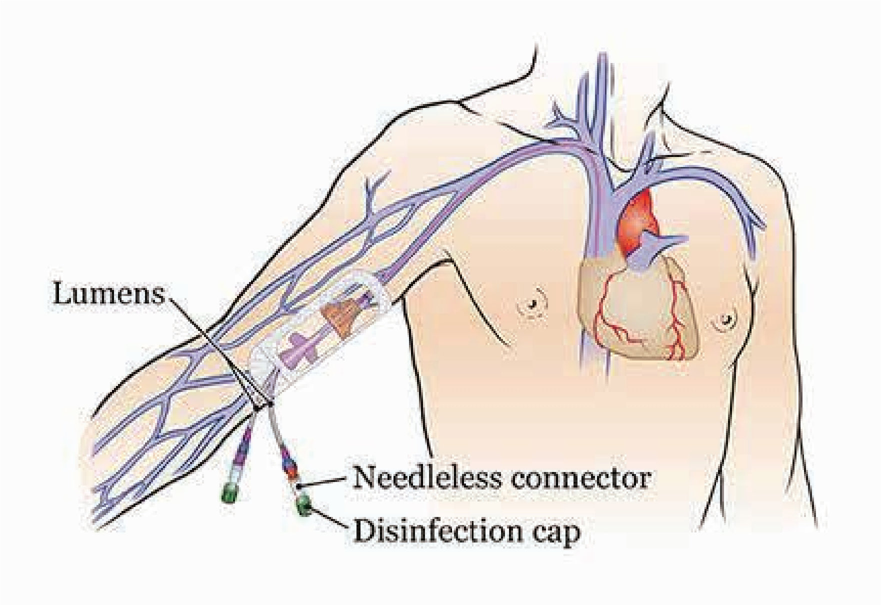
Use a waterproof PICC line cover or wrap the arm with plastic wrap and tape. Avoid submerging the arm in water.

8. What sleeping positions are best with a PICC line?

Avoid lying on the arm with the PICC line and avoid folding the arm under or over the head during sleep.

9. Are there any activities or precautions to follow with a PICC line?

- Avoid lifting heavy weights or swimming with the PICC line in place.
- Wear loose-fitting clothes to avoid pulling on the line.
- Try to avoid administering PET scan dye via the PICC line; use a peripheral cannula instead.



13. PSYCHOSOCIAL ISSUES

1. Will my family and friends accept or understand my current situation?
It is natural to worry about how others will react, but most families and friends try to be supportive. Open communication can help them understand your situation better, and it's okay to express your feelings and needs. If needed, a counsellor or social worker can facilitate these conversations.

2. Can my disease spread to my loved ones?
No, cancer is not contagious and cannot spread to your loved ones. You can safely spend time with family and friends without worrying about them contracting the disease.

3. Will I be able to eat normally in public?
Depending on your condition, your ability to eat in public may vary. If you are managing symptoms like nausea or difficulty swallowing, you might need to make adjustments to what and how you eat. Consult with your Palliative Care team for personalized advice.

4. Who will take care of my family after I'm gone?
Many patients worry about the future of their families. It's helpful to have open discussions about future plans, including financial and emotional support. You can work with legal advisors or social workers to ensure proper arrangements are in place and do advance care planning (ACP) discussions.

5. How will I cope with the burden of the disease?
Coping with the burden of a serious illness can be overwhelming, but you don't have to face it alone. Palliative care teams, counsellors, and support groups can provide emotional and practical support to help manage the physical, psychological, spiritual, social and emotional challenges of your illness.

6. Is my disease a result of past sins?
- Illness is not a punishment for past actions or sins. Cancer, like many diseases, can occur due to various factors, such as genetics, environment, or lifestyle, but it is not a reflection of one's moral or spiritual past.

7. Will my partner still be sexually attracted to me?
Concerns about intimacy are common, especially when dealing with physical changes or emotional stress. Open communication with your partner about desires and limitations can help. Healthcare professionals can offer guidance on how to maintain intimacy despite the illness, and it's important to have compassionate discussions about your feelings.

8. Is it safe to have sex while undergoing chemotherapy?
It is generally safe, but chemotherapy can cause cytotoxic waste to be excreted through bodily fluids. For your partner's safety, it is recommended to use barrier protection (such as condoms) for the first 48 hours after completing chemotherapy.

9. Is it safe to cuddle, kiss, or hold my grandchildren while undergoing radiotherapy?
External beam radiotherapy does not make you radioactive, so it is safe to have close physical contact with others, including grandchildren, after treatment. However, if you have temporary internal radiation implants, you should avoid close contact with children, pregnant women, and limit visitor interaction while the implants are in place. If you have undergone radioactive scan like I131 for thyroid cancer then, close contact with children and pregnant woman. If radioiodine therapy has been given, avoid contact with children for 1 week.

10. Am I not receiving any treatment during the hospice phase?
In hospice care, the focus shifts from curative treatment to comfort care. This does not mean you are not receiving treatment; rather, the care is focused on symptom relief and improving your quality of life.

11. Am I doing enough for my patient?
It is natural to feel unsure, but according to the WHO's definition of palliative care, patients have the right to receive symptom relief, psychosocial support, and an improved quality of life, regardless of whether curative treatment is still ongoing. Palliative Care is essential for your loved one's comfort and well-being.

12. Will I be able to express my feelings to my loved ones during their final moments?
Many people fear they won't have the chance to say what they feel

before their loved one passes. Palliative Care can help to express your feelings early and openly while they are still able to listen and respond. Written notes, gestures, or shared moments can also convey your love and support.

13. Is it justified to leave my patient with a nursing attendant while I am at work?

Yes, it is common for family members to rely on nursing attendants for care when they are unable to be present. This ensures that the patient receives consistent care, and it's important to remember that you are still involved in their care even when you are not physically there.

14. Is it normal for my loved one not to talk or respond to friends and family near the end?

Yes, it is common for patients to withdraw and become less communicative near the end of life. This is often a way for them to detach from their surroundings as they focus on their own internal experience. It is a natural part of the dying process.

14. FINANCIAL PLANNING AND MANAGEMENT

1. What are the common financial challenges faced by families after a cancer diagnosis?
Families often face substantial direct costs, including OPD charges, follow-up visits, investigations, second opinions, hospital stays, surgeries, chemotherapy, radiation, medications, and pain or palliative care. Indirect costs, such as loss of income (if the patient or caregiver stops working), transportation, and lodging for distant treatment, also add up. Out-of-pocket expenses for specialised care, alternative treatments, and supportive therapies can further strain finances.

2. How does the financial burden of cancer treatment impact families?
The financial burden can severely strain families, causing emotional stress, depletion of savings, and reduced income as caregivers or patients may need to take time off work. Many face medical debt and must adjust to a more restricted lifestyle. This financial pressure can affect family well-being, strain relationships, and lead to mental health challenges like anxiety and depression.

3. How should one prepare financially if a family member is diagnosed with cancer?
After a cancer diagnosis, accepting the reality of the disease is crucial for both emotional and financial planning. Assess your financial situation early and prepare to manage costs effectively. Start by reviewing health insurance coverage, including treatments, medications, and out-of-pocket expenses. Explore government schemes, NGO support, hospital financial assistance programs, and employer benefits like paid leave or disability support. Creating a detailed budget is essential. Include expenses like hospital bills, medications, transportation, and caregiving. Identify assets and categorize them as liquid (cash, savings), semi-liquid (stocks, mutual funds), and illiquid (property, long-term investments). Liquid and semi-liquid assets can be accessed quickly for immediate needs, while illiquid assets can be used for long-term planning, including credit lines or loans against securities. Establishing an emergency fund, anticipating income loss, and seeking financial advice are key to managing both short- and long-term financial strain.

4. Why is tracking my expenses important during cancer treatment? How can it help?
It helps provide clarity on where money is being spent, particularly on treatments and medications. By keeping a clear budget, you can prioritize necessary expenses, avoid debt, and make informed decisions about financial assistance and treatment options. Budgeting offers peace of mind by giving you control over your finances, allowing you to focus on recovery.

5. What costs can I expect during palliative care for a terminal illness?
Palliative care costs vary based on whether care is at home or in a healthcare facility. Expenses may include medications, hospital visits, transportation, consultations, and psychosocial support. While these costs can escalate, especially with specialized treatments (MIPSIs), palliative care is generally less expensive.

6. Does health insurance cover all cancer-related expenses? Does insurance help with palliative care expenses?
While health insurance can ease the financial burden, it often doesn't cover all cancer-related expenses. Some policies may exclude certain treatments, medications, or second opinions, and patients may face high deductibles or copayments. It's essential to review your policy carefully and clarify coverage limits and exclusions and exemptions with your insurer. Most comprehensive policies cover some aspects of palliative care, especially hospitalisation. However, coverage for home-based care or daycare procedures varies. Some policies offer riders or add-ons for terminal illness coverage, providing additional financial relief.

7. How can I effectively utilize my health insurance for cancer treatment without exceeding coverage limits?

To effectively use your health insurance, start by understanding your policy details, including hospitalisation coverage, treatment caps, room rent caps and copayment clauses. Opt for network hospitals to benefit from cashless treatments, and ensure you get pre-authorizations for major treatments. Regularly monitor your coverage usage and consider adding top-up or critical illness plans if your base policy is insufficient. Keep detailed records of all claim submissions, and explore additional financial aid options, such as government schemes like PM and CM funds, Ayushman Bharat or NGO support programs. This will help maximize your coverage and minimize out-of-pocket expenses.

15. ADVANCE CARE PLANNING (ACP) AND ADVANCE DIRECTIVES (AD)

1. What is Advance Care Planning (ACP)?

ACP is a process in which individuals discuss their future healthcare preferences with family, caregivers, and healthcare professionals. It allows people to express their wishes regarding medical treatment in case they become unable to make decisions due to illness or incapacity. This is especially important for patients with chronic or life-limiting diseases like cancer, ensuring that medical care aligns with the patient's values and preferences.

2. Who is Advance Care Planning for? Do I have to be terminally ill to have an ACP in place?

ACP is beneficial for everyone, regardless of age or health status. ACP is not limited to terminally ill patients - healthy individuals can also benefit from having a plan in place in case of an accident or unexpected medical event.

3. How is Advance Care Planning beneficial?

ACP allows individuals to maintain control over their healthcare decisions even if they lose the capacity to make decisions. It upholds patient autonomy by ensuring that treatment aligns with their preferences. ACP also reduces the emotional burden on families by providing clear documentation of the individual's wishes, helping to avoid confusion or conflict during emotionally challenging times. It also helps the Palliative care team ensure that medical interventions align with the patient's goals, such as prioritizing comfort or avoiding aggressive treatments in certain situations.

4. When should I start Advance Care Planning?

ACP can be started at any time, and there is no wrong moment to begin. Early planning provides peace of mind and ensures that healthcare preferences are documented long before they are needed.

5. What is an Advance Directive? How is an Advance Directive different from a living will?

An Advance Directive (AD) is a legal document in which individuals outline their preferences for medical treatment in case they become unable to make decisions for themselves. It can specify preferences regarding life-sustaining treatments, resuscitation, organ donation, and other medical interventions. In India, the Supreme Court recognizes the legality of Advance Directives, allowing individuals to express their treatment preferences in advance, making it easier for families and doctors to honour their wishes, especially regarding end-of-life care.

A living will is a part of Advance Directive that focuses on the types of medical treatments an individual would or would not want in the future if they are unable to express their wishes. Another part of an Advance Directive is the appointment of a healthcare power of attorney, where someone is designated to make medical decisions on behalf of the individual if they become unable to do so. This designation of healthcare power of attorney can occur in a separate document or along with a living will.

6. What should be included in an Advance Directive?

An Advance Directive should include:

- Specific instructions regarding life-sustaining treatments such as ventilators, feeding tubes, artificial nutrition, dialysis, and resuscitation.
- Conditions under which these treatments should be withheld (e.g., terminal illness, irreversible coma).
- Preferences on pain management and palliative care.
- Designation of a healthcare proxy or decision-maker if the individual becomes unable to communicate.
- Any religious or cultural considerations related to care.

7. How can a family create an Advance Care Directive for a loved one with cancer or another terminal illness?

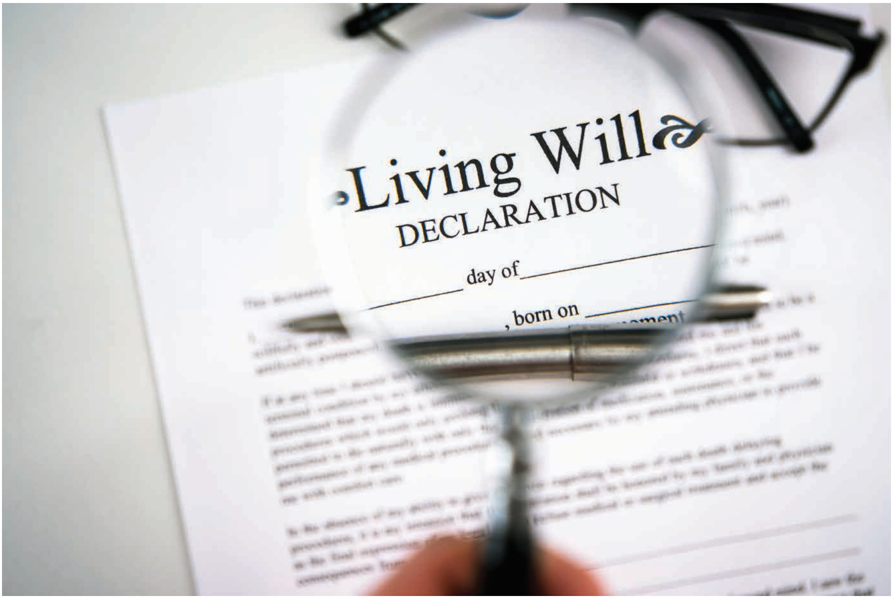
To create an Advance Care Directive (ACD) in India:

- The patient must draft the directive while in a sound state of mind, outlining their preferences regarding future medical treatments.
- The document must be signed by the individual and attested by two independent witnesses, and attested before a notary
- The witnesses and the notary or “Gazetted Officer” shall verify the directive and certify its authenticity that it has been executed voluntarily and without any compulsion with full understanding of all relevant information and its consequences.

- Copies of the directive should be shared with the individual's family members, caregivers, and medical team to ensure they are aware of the patient's wishes.

8. How do I ensure my Advance Directive is followed?

To ensure your Advance Directive is followed, make sure it is clear, legally valid, and shared with your healthcare providers and family members. It is also a good idea to revisit and update the directive regularly as your health situation changes.



> ***You matter because you are you, and you matter to the last moment of your life. We will do all that we can not only to help you die peacefully, but also to live until you die.***
>
> ***Dame Cicely Saunders***

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