NCG Palliative Care Guidelines – End of Life Care

References to understand the context of End of Life Care guidelines.

1. Definition of terms used in limitation of treatment and providing palliative care at end of life: ICMR EOLC.pdf (ncdirindia.org)
2. ICMR Consensus Guidelines on 'Do Not Attempt Resuscitation' - file:///C:/Users/Nandini/Downloads/ICMR_Consensus_Guidelines_on_Do_Not_Attempt_Resus.pdf
3. Prognostication in Advanced Cancer: Update and Directions for Future Research – Dr Hui et.al - https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6500464/
4. Improving End-of-Life Care & Decision-Making - http://ficci.in/spdocument/23114/FICCI-ELICIT-Guide-for-Doctors-and-Administrators.pdf
5. Analysis of the common cause judgment: would living wills become a practical reality? http://ili.ac.in/pdf/hc.pdf

Individualised Approach to dignified End-Of-Life Care

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Identify dying phase. Complete communications, ensure insight, document discussions. Consider de-escalating invasive interventions

Simultaneously assess and plan routine care– review & update plan daily: Care of bedridden patient, comfortable position; skin care /air-bed to prevent pressure sores; Bowel/ Bladder / bowel regimes; assess /manage urine retention/ incontinence/ constipation. Fluids matched with urinary output. Oral sips as possible, parenteral - not > 500-1000cc of NS / 24 hours - avoid over-hydration concerns – aspiration, oedema, bladder distension, and dyspnoea.

Patient in advanced stage; no disease-modifying options, and constantly worsening general condition, poor functions, bed-ridden, no feeds,disinterested/ withdrawn, ± deteriorating vitals- low B.P, cold skin, jaw-breathing/ Cheyne–Stokes breathing. Take 2nd opinion if signs are ambiguous

Patient - Assess patient's concerns at physical, emotional, social and spiritual realms

Which are the most distressful physical Symptoms and Distresses?

Are there psychosocial and spiritual concerns or Distresses?

Listen actively for wishes, preferences. Support through empathetic communications. Avoid philosophising & comparing. Provide access to emotional support; & to spiritual /religious support.

Family - Check for Advance Care Directives/ expressed wishes. Check for healthcare proxy / surrogate decision maker. Check for and ensure prognostic insight of the family/ significant other. Does Family have concerns? - clarify/ respond.

Reflect on survival using prognostication tools (https://www.predictsurvival.com) and the 'Surprise question'. Respond to questions on expected survival in probabilistic terms..

Use communication Skills - SPIKES, Ask-Tell-Ask approach. Convey in light of their values. Mix information sharing with maintaining Hope (comfort/dignity). Emphasise uncertainty

Explain regarding reduced requirements for nutrition and hydration. Express empathy and respond to their concerns.

Which is the preferred place / setting for further care? - Hospital, home, hospice? Would this family require bereavement support?

Assess for supportive care needs - identify and address the needs for information, communications, nursing care, assistance with practical needs and contexual support e.g. visit by a grandchild. clinically assisted hydration may have a role in selected situation.

Eliminate non-essential medications (e.g. anticholesterol) and non-essential nursing regimens e.g. routine checking of blood sugar, vital parameters/ SpO_2 at regular intervals

Individualised Approach Symptom-free End-Of-Life Care

Assess physical symptoms and distresses and review needs periodically. Use Anticipatory prescriptions for better control of symptom. Utilise routes for uninterrupted medications . Contiuous Subcutaneous Infusion (**CSCI**) is a useful route in patients who are non-oral.

- •Secretions/Noisy Breathing/death rattle –Glycopyrronium, nebulization of normal saline, Hyoscine butyl bromide, octreotide. Furosemide if required for pulmonary edema
- •Gastric reflux- Metoclopramide (avoid concurrent use with Hyoscine butyl bromide)/Ranitidine
- •Terminal delirium/ altered consciousness- Haloperidol, olanzapine, benzodiazepines . If intractable, CSCI- Haloperidol, Midazolam
- •Pain- Activate pain algorithm. Plan uninterrupted analgesia using non-enteral routes - CSCI
- •Dyspnoea- (Dyspnoea Algorithm) - or is it pulmonary edema?
  - •CSCI- Opioids, Benzodiazepines.
  - O2 Supplementation if hypoxia present, only if it provides symptom relief and comfort. Explain the goal prior to strating; and discontinue early if unhelpful
  - Furosemide for edema and pulmonary edema
- •Nausea/Vomiting - (Nausea, Vomiting Algorithm)
  - CSCI- Haloperidol, Hyoscine Butyl bromide, metoclopramide, octreotide, ondansetron
- Managing terminal events
  - Consider Palliative sedation for intractable symptoms - complex pains, breathlessness, agitation - details below
  - Bleeding (Major vessel blowout, Haematemesis, haemoptysis)-Midazolam S/C, I/V, supportive care
  - Seizures-
    - Benzodiazepines- Inj.Midazolam stat and CSCI
    - Anti-epileptics- Phenytoin, Phenobarbitone infusion

Palliative Sedation Decision making Algorithm [1] [2]

[1] Refractory symptoms: All possible treatments have failed; or there are no available methods for palliation within the time frame and the risk-benefit ratio that the patient can tolerate
[2] https://palliative.stanford.edu/palliative-sedation/medications-of-choice/

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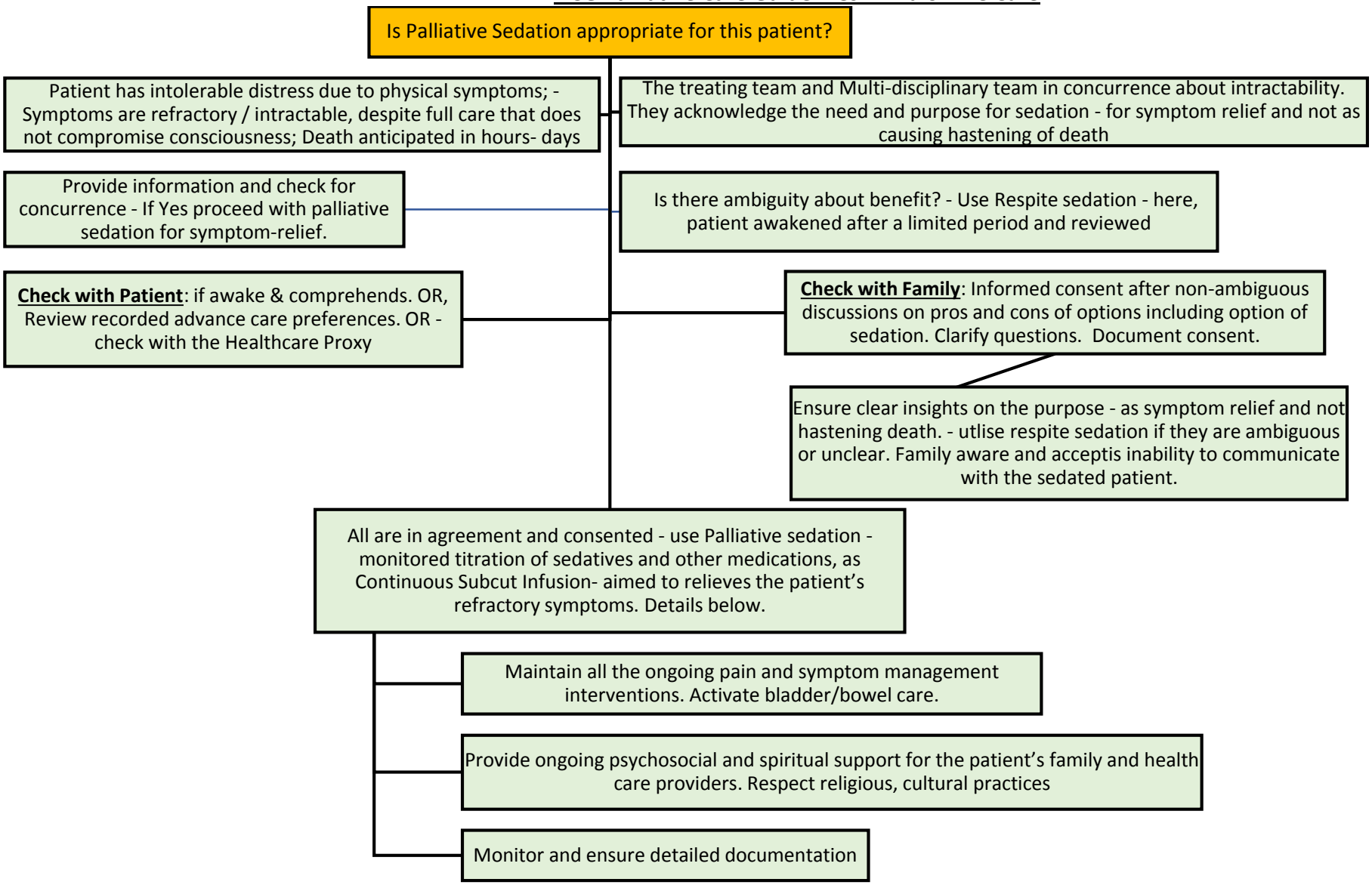
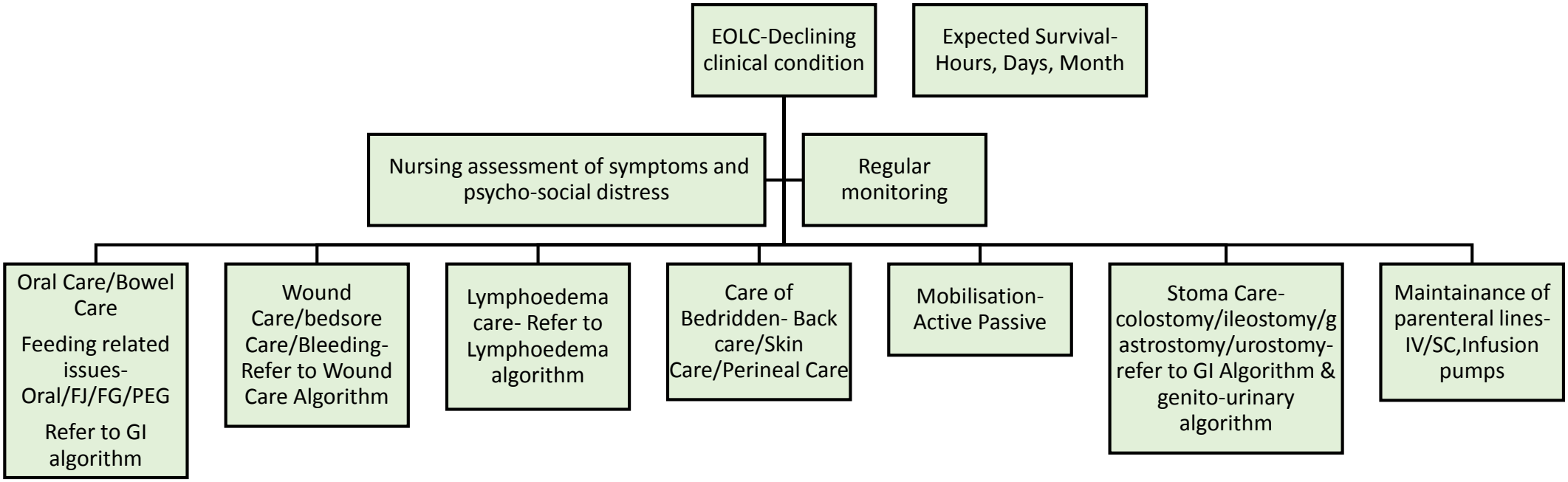


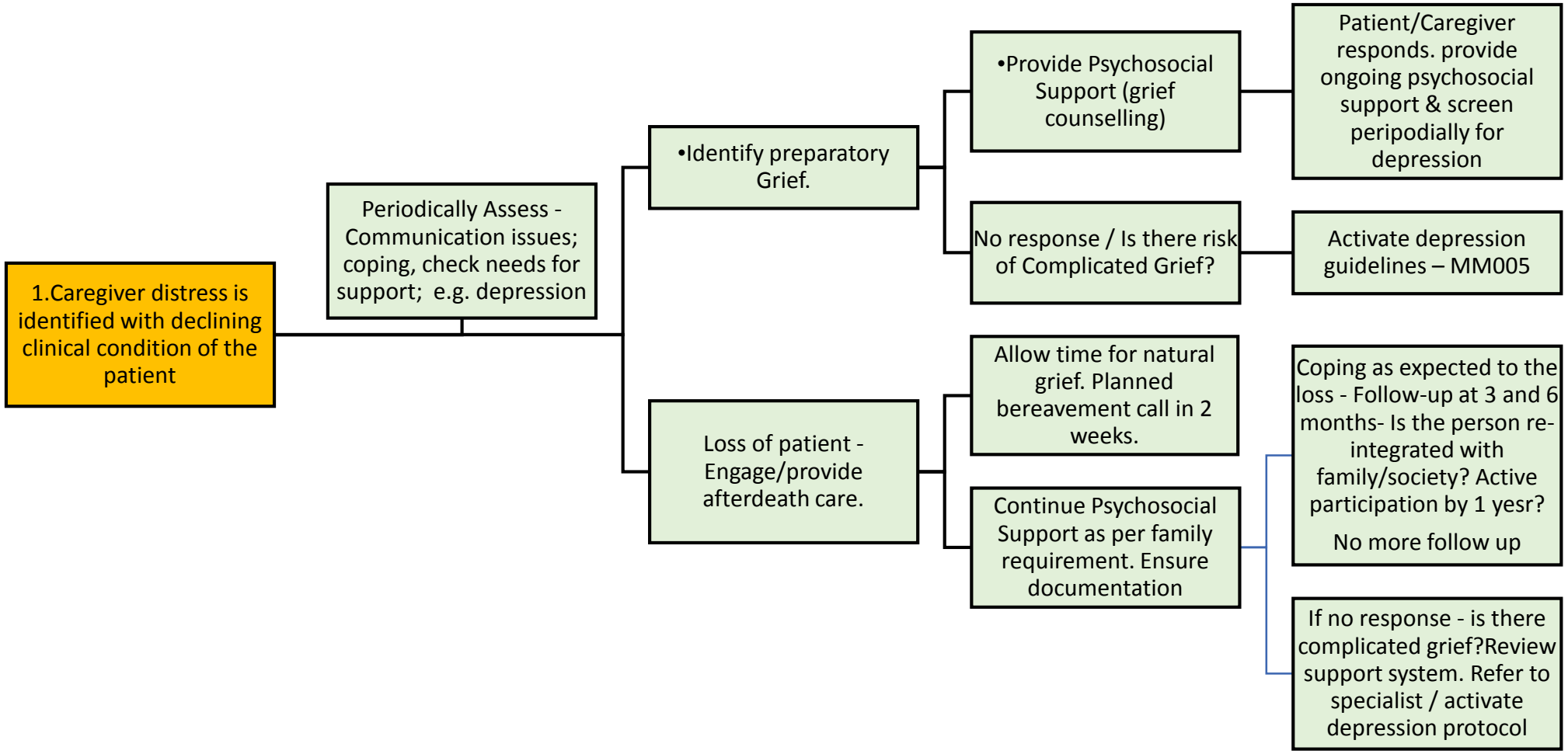
Approach to End-Of-Life Nursing Care:



Nursing -EOLC

- Nursing assessment- physical /psycho-social/spiritual and plan procedures
  - Oral care- mucositis/oral candidiasis/xerostomia – (salt soda gargle/candid mouth paint/artificial saliva)-refer to GI algorithm
  - Bowel care- constipation-enema (high up enema) manual evacuation/ colostomy/ileostomy care- refer to GI Algorithm
  - Wound care- bedsore care/infestations(maggots)/infections refer to wound care algorithm
  - Care of bedridden- mobility(active/passive) back care/ perineal care
  - Bladder care – catheter care/bladder wash/ urostomy care
  - Lymphoedema care – maintain skin care, covered dressing on areas of leakage, positioning
- Monitor - comfort/psychological wellbeing of patient and caregiver

Approach to Grief/ Bereavement Support


1.Caregiver distress is identified with declining clinical condition of the patient
Periodically Assess - Communication issues; coping, check needs for support; e.g. depression
•Identify preparatory Grief.
•Provide Psychosocial Support (grief counselling)
Patient/Caregiver responds. provide ongoing psychosocial support & screen peripodially for depression
No response / Is there risk of Complicated Grief?
Activate depression guidelines – MM005
Loss of patient - Engage/provide afterdeath care.
Allow time for natural grief. Planned bereavement call in 2 weeks.
Continue Psychosocial Support as per family requirement. Ensure documentation
Coping as expected to the loss - Follow-up at 3 and 6 months- Is the person re-integrated with family/society? Active participation by 1 yesr?
No more follow up
If no response - is there complicated grief?Review support system. Refer to specialist / activate depression protocol

Medicines Used Commonly During Terminal Stages[3]

- Use an **individualised** approach. Prescribing anticipatory medicines based on symptoms expected and setting of care (e.g. home). Specify the indications for use and the dosage of any medicines prescribed. Review regularly and adjust dosages as per requirements.
- Assess route of drug administration - Subcutaneous /Sublingual/ PR/ IV. For ongoing symptoms - Prefer continuous sub-cutaneous Infusion (CSCI).

TERMINAL SEIZURE	MAJOR HAEMORRHAGE	TERMINAL BREATHLESSNESS
It is usually inappropriate to investigate during the terminal stages. To prevent further seizures, commence midazolam 20-30mg/24hrs subcutaneously via syringe driver over 24hrs. Prescribe midazolam 5-10mg buccal or 5-10mg SC/IM as required for SOS seizure control. Alternatively or additionally, sodium valproate and/or levetiracetam via the subcutaneous route.	Bleeding occurs in 14% of patients with advanced disease. Also refer to NCG guidelines on managing bleeding in oncology patients It is a terminal event in approximately 6% patients. Anticipate bleeding in a pre-disposed patient (neck, inguinal, internal organs infiltrating vascular structures) with H/O sentinel bleeding; use the crisis box. If resuscitation is inappropriate (futile) • Maintain calm. This will reflect on the environment and influence the patient (if conscious) / care-givers. • The treating team should maintain presence with the patient/family, giving support and explanation. • Use dark towels to absorb blood loss – reduces visual impact of catastrophic blood-loss.	**Patient not already on opioid: -** Give morphine 2.5mg SC stat. Followed by 2.5mg SC 1-hrly as required Start morphine 10mg/24hrs SC by syringe driver **Patient already on opioid :-** 10 to 20 % of the baseline daily requirement of opioid, calculated in morphine equivalents, and given every 4 hours has been recommended. **Midazolam** 2.5mg SC stat; Followed by midazolam 2.5mg SC 1-hrly as required. Start midazolam 10mg/24hrs SC as infusion / syringe driver This is especially a useful option in patients with renal impairment. If breathlessness persists - combine opioid with midazolam **Review within 24hrs;** • if 1-2 breakthrough doses of morphine or midazolam were needed due to breathless episodes in the
NAUSEA & VOMITING Haloperidol -1.5mg SC once or twice daily Hyoscine butyl-bromide 20mg SC 1-hrly doses titrated as required Octreotide as 2nd line if the symptoms do not improve within 24 hours		

[3] https://www.nice.org.uk/guidance/ng31/chapter/Recommendations

STOPPING NON ESSENTIAL MEDICATIONS All medicines that are not essential for symptom relief, but are impacting patient comfort or are likely to cause complications should be discontinued. For example – continuing hypoglycemics in a long-term diabetic, who is no longer feeding – can cause hypoglycemia and its complications. **Individualize the de-prescription.**	• Midazolam 10mg (appropriate route - IV/IM/SC/buccal/sublingual) to relieve distress in a patient that may be imminently dying. • Family needs great deal of emotional support	previous 24hrs, increase syringe driver dose by 30-50%. • If 3 or more breakthrough doses were needed in the previous 24hrs, consider doubling syringe driver dose of drug in use and increase breakthrough dose to 5mg. • Use breakthrough doses hourly as required. • Ongoing review is mandatory. If symptoms are intractable consider palliative sedation/ seek specialist palliative care advice. **If Pulmonary edema suspected**: Furosemide – Per Oral or I.V - Infusions have better results. If oral/ IV routes unavailable, off-label use of Sublingual / Subcutaneous / nebulization routes.
EXCESSIVE OROPHARYNGEAL / RESPIRATORY SECRETION	**TERMINAL DELIRIUM**	**PALLIATIVE SEDATION**
Utilise lateral positioning to let the secretions flow **Drug Options:**	**Drugs**: Haloperidol & if required Midazolam. Haloperidol: 1.5mg SC once or twice daily. And review within 24 hrs. If symptoms are controlled, continue SC dose either as stat OR as 12-24hrly OR via syringe driver	Medications may be administered orally (until the patient is sedated), sublingually, rectally, intravenously, or subcutaneously, with the route usually dependent on patient condition and clinician preference. The opioid administration is usually continued once palliative

<table>
<tr>
<td rowspan="2">Hyoscine butyl bromide 20mg SC 1-hrly doses titrated as required
OR
Glycopyrronium 200 micrograms SC 1-hrly doses titrated as required
OR
Specify maximum 6 doses/24hrs – frequent need should prompt review
↓
Regular treatment via syringe driver:
Hyoscine butyl-bromide 60mg/24hrs
OR
Glycopyrronium 600 micrograms/24hrs

Extra doses (SC up to 1-hrly as required, maximum 6 doses in 24hrs)
Hyoscine butylbromide 20mg SC
OR
Glycopyrronium 200 micrograms SC
↓
Review after 24hours or sooner
If extra doses needed, increase the 24hr dose to: Hyoscine butyl-bromide 120mg/24hrs

OR
Glycopyrronium 1200 micrograms/24hrs

Monitor & manage - Dry-mouth, delirium, urinary retention, excessive sedation</td>
<td>Midazolam 2.5mg - 5mg SC stat when anxiety or agitation predominate.
Initiate syringe driver: Midazolam 10-20mg/24hr SC.
Breakthrough dose: Midazolam 1.5mg - 5mg SC up to 1-hrly - doses titrated as required (use lower dose in frail/elderly patients)

Titrate / increase midazolam syringe driver dosing as estimated as equivalent to total breakthrough doses / previous 24 hours.
If midazolam requirement is > 30mg/24hrs – consider adding haloperidol 1.5 – 5mg/24 hrs SC.

Review within 24 hrs
*If symptoms are controlled, continue SC either as stat doses 12-24hrly or via syringe driver

*If symptoms are not controlled, increase haloperidol to 5mg/24hrs SC, and continue breakthrough doses of midazolam 5mg SC 1-hrly with doses titrated as required.</td>
<td rowspan="2">sedation is initiated, at doses converted for the respective route.

Benzodiazepine
Midazolam: Start as 0.5–5 mg bolus IV/SC, then continuous infusion at 0.5–1 mg/h; usual maintenance dose 10-20mg/24 h; titrated to effect. Max. dose 200mg/24 h.
Breakthrough dose = 5-10mg.
Lorazepam: 0.5–2 mg PO, SL, every 1–2 hours if parenteral route unavailable.
Anti-psychotics
Haloperidol: Start as 0.5–5 mg SC every 2–4 hours OR as continuous infusion; 5-20mg/24 h after initial dose - 1–5 mg bolus IV/SC.
Breakthrough dose - 2.5 to 5mg.
Olanzapine: 10-20mg/day S/C

General Anesthetic agents: These are as 3rd line when drugs, including benzodiazepines, fail to produce satisfactory symptom relief.

Barbiturates: when intractable pain, seizures as intractable symptoms
Phenobarbitone: 200 mg IV/SC bolus, then CII/CSI at 600 mg/d; usual maintenance dose, 600–1,600 mg/d
Thiopental: 5–7 mg/kg bolus IV, then CII at 20 mg/h; usual maintenance dose, 70–180 mg/h
Propofol: Useful specifically as an adjuvant sedative in patients with nausea vomiting, pain or agitation as intractable symptoms.</td>
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<td>Olanzapine or chlorpromazine 25 mg IV/IM every six hours may be helpful if sedation is a desired side effect.</td>
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		It is used when Midazolam, neuroleptics, and barbiturates have proved ineffective. Benefits: antiemetic, bronchodilatation, and itching control benefits. Dose: Infusion, gradually titrated in steps of 0.5 mg/kg/h after an initial dose of 0.3- 0.5 mg/kg administered over 3-5 min; titrated every 15-20 minutes to the grade of sedation required. Max dose not > 4 mg/kg/h and the duration of infusion not > 48 hours Caution: hypotension, twitching, seizures. Lower dose in elderly.