Palliative extubation and end of life symptom management

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INTRODUCTION

Palliative extubation (PEx) is the withdrawal of invasive mechanical ventilation support with the primary aim of providing comfort and allowing natural death to occur. It can be considered when further aggressive medical care appears futile and does not meet the desired goals of care for a ventilator-dependent patient (1). PEx is a complex process, which involves multiprofessional team participation, adequate planning, communication skills, and advanced knowledge of symptom control. If PEx is poorly handled, it may cause distress for the patient, patient's family and even healthcare personnel. However, there are limited data on how to perform PEx (2).

Stages of palliative extubation

A. Shared decision for palliative extubation
B. Preparation for palliative extubation
C. Palliative extubation process
D. Post-palliative extubation period

STAGE A. SHARED DECISION FOR PALLIATIVE EXTUBATION

Multidisciplinary meeting (Physicians, paediatric palliative care services, medical social worker)	• Establish the irreversibility of patient's condition, rule out all possible therapeutic options, and achieve consensus regarding indication for PEx. • Feasibility of offering PEx at home or hospice. Involve community palliative support (Starpals) early if planned for home PEx. • Possibility of survival after PEx with appropriate parallel planning. • Consider need for coroner's case, option of academic post-mortem examination and/or organ donation, if appropriate.
Family conference	• Use a respectful, empathetic and culturally sensitive approach to end of life discussion. • Generate shared goals of care with patient and family regarding end of life with recommendations of withdrawal of mechanical ventilation from medical team. • Establish do not resuscitate (DNR) status. • Explore end of life care wishes and offer choice of place of extubation if appropriate. • Prepare family for possible outcomes of ventilator withdrawal. • Allow some time for family to prepare themselves before following up to reach agreement on timing of extubation. • Prepare family regarding need for coroner's Sym
Documentation	• Emphasize in the medical records for DNR and not for escalation life-prolonging measures, such as resuscitation, hemodialysis, inotropes, vasopressors, etc. • Rationalise medications and blood monitoring.

STAGE B. PREPARATION FOR PALLIATIVE EXTUBATION

Patient & Family-centered approach

- Arrange for single room and allow family visitation.
- Encourage parental participation in simple daily care activities.
- Allow family to carry/hold patient prior to extubation, if feasible.
- Offer memory building activities/legacy work (e.g. Family photographs, handprints, etc).
- Explore and carry out any special wishes, including religious ceremonies, rituals or prayers.
- Ongoing psycho-emotional support for family (including siblings) by MSW and paediatric palliative care service.

Rationalise medical interventions

Medical interventions	Management
Medications and interventions	• Suspend non-essential medications. • Stop blood monitoring. • Stop any ongoing invasive interventions such as dialysis.
Fluids • Excessive hydration may result in unwanted side effects such as edema, increased respiratory secretions and gastric secretions (3).	• Reduce total fluids (Intravenous or enteral feeding) to 50% total daily fluid requirement. • Consider diuretics (frusemide 1mg/kg/dose PRN) – not suitable for hypotensive patients.
Nutrition • Providing food and hydration is often part of parental instinct to nurture their child but can also lead to unwanted complications at end of life (3).	• Discuss pros and cons of enteral feeding if family requests to continue feeding. • Reduce total fluids (Intravenous or enteral feeding) to 50% total daily fluid requirement.
Neuromuscular blockade	• Discontinue at least 2 hours before extubation. Do not proceed with extubation if there are any remnant effects of paralysis. • Duration of action of the neuromuscular blocking agents may continue up to 18 hours in patients with multi-organ failure (2).
Patients at risk of post extubation stridor • ETT Cuff leak <10% • Glasgow Coma Scale ≤ 6 • ≥ 5 days of mechanical ventilation • Difficult intubation with risk of laryngeal edema	• Prescribe dexamethasone 0.2mg/kg Q12H x 3 doses (at least 2 doses before extubation if possible).

Symptom management

- Ensure there is an intravenous (preferable) or subcutaneous access (2) for administration of medications.
- Use both pharmacological and non-pharmacological methods to ameliorate end of life symptoms. *Refer to Table 1 for doses.*
- Ensure medications are prepared just before extubation process so that they are readily available for immediate use to relieve symptoms.
- There is no evidence suggesting that the administration of benzodiazepines and/or opioids influence the time to death following extubation (2).

Table 1: Medications for symptom control (4)

<table>
<tr><th>Symptoms</th><th>What to use?</th><th>When to start?</th></tr>
<tr><td rowspan="3">Pain and/or Dyspnoea</td><td>Non-pharmacological measures
Pain: Massage, repositioning, distraction
Dyspnoea: Elevate the head of the bed, good aeration, fluid restriction, gentle suction</td><td></td></tr>
<tr><td>Pharmacological measures: Opioids
(i) Morphine
If opioid naïve (≤ 1 week): Start with lower dose and up titrate as necessary
If already on infusion: titrate according to response and add in breakthrough doses PRN
Baseline dose<table><tr><td>Intermittent (IV/SC)</td><td>Neonate: 0.025mg/kg/dose Q6-8H
≥ 1 month: 0.05 – 0.1mg/kg/dose Q4H
Max dose 5mg/dose</td></tr><tr><td>Infusion (IV/SC)</td><td>10-40mcg/kg/hr</td></tr></table>Breakthrough dose:
8-10% total daily dose (TDD) Q1-4H PRN (max 5mg), increase baseline if ≥ 3 doses required
E.g. 1 year old (10kg) on baseline IV morphine 20mcg/kg/hr
TDD = 4800mcg per day
Breakthrough dose (8% TDD): 380mcg = 0.38mg Q1-4H PRN (round up to 0.4mg Q1-4H PRN)</td><td>Onset (IV/SC): 5-10 min
Duration of action (IV/SC): 2-4hours

Before extubation: Start baseline opioid at least 6 hours before extubation, continue if patient is already on.

Post extubation: Titrate opioid according to effect.</td></tr>
<tr><td>ii) Fentanyl
Preferred choice in renal/liver dysfunction
Baseline Infusion (IV/SC)
Basal infusion: 0.25 – 1mcg/kg/hr
Usually not given in intermittent doses due to short duration of action
Breakthrough dose:
8% of TDD Q2H PRN as slow bolus (over 3-5 min)
E.g. 1 year old (10kg) on baseline IV fentanyl 0.25mcg/kg/hr
TDD = 60mcg per day
Breakthrough dose (8% TDD): 4.8mcg Q2H PRN (round up to 5mcg Q2H)
For all subcutaneous infusion, consider volume of infusion per hour
Infusion rate should be ≤2ml/hr for infants & children, ≤3ml/hr for adolescents
Increase medication concentration, combine medications in one infusion or use 2 different subcutaneous sites if maximum infusion volume is exceeded.</td><td>Onset (IV): Almost immediate
Duration of action (IV): 0.5-1hr

Before extubation: Start baseline opioid at least 6 hours before extubation, continue if patient is already on.

Post extubation: Titrate opioid according to effect.</td></tr>
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<table>
<tr><td rowspan="3">Anxiety
Agitation
Restlessness</td><td>Non-pharmacological measures:
• Familiar people/objects, low lighting, soothing tones, music, decreased monitoring</td><td></td></tr>
<tr><td>Pharmacological: Benzodiazepines
(i) Midazolam
• Dose used for anxiety/agitation usually 25-50% of conscious sedation dose
<table><tr><td>Intermittent (IV/SC)</td><td>0.025-0.05mg/kg/dose PRN over 2-3 mins
Minimum interval:
• IV: Q15mins
• SC: Q30mins
Max dose:
• 1month - 5years old: 6mg
• 6 - 11 years: 7.5mg
• ≥12 years: 10mg</td></tr><tr><td>Infusion (IV/SC)</td><td>0.5-2mcg/kg/min</td></tr></table></td><td>Onset:
• IV: 1-5 mins
• SC: 5-10min
Duration of action: 1-2 hours

Before extubation:
• If on infusion for sedation: reduce to minimum dose required for comfort
• if not on infusion: intermittent doses for symptom control

Post extubation:
• If on infusion: Titrate according to effect
• If not on infusion and agitation/restlessness is expected: prescribe intermittent doses</td></tr>
<tr><td rowspan="2">Secretions</td><td>Death rattle (gurgling sound) is a common phenomenon at the end of life.

Non-pharmacological measures:
• Repositioning the head, fluid restriction, gentle suction</td><td></td></tr>
<tr><td>Pharmacological: Anticholinergics
(i) Glycopyrronium bromide (glycopyrrolate)
<table><tr><td>Intermittent (IV/SC)</td><td>4-10mcg/kg/dose
Interval:
• 1 month-11years: Q6-8H PRN
• ≥12 years: Q4-6H PRN
Max dose:
• 1month-11years: 200mcg/dose Q6H
• ≥12 years: 200mcg/dose Q4H</td></tr><tr><td>Infusion (IV/SC)</td><td>Usually not used</td></tr></table></td><td>Onset (IV): 1-5 mins
Duration: 7 hours

Before extubation: Give a stat dose 30 minutes before

Post extubation: Intermittent doses for death rattle</td></tr>
<tr><td rowspan="2">Nausea/
Vomiting</td><td>Non-pharmacological measures:
• Avoid noxious smells</td><td></td></tr>
<tr><td>Pharmacological: Antiemetics
(i) Ondansetron
• Intermittent (IV): 0.1 – 0.2mg/kg/dose Q8H
• Max dose for 4mg/dose (can allow up to 16mg/dose for severe nausea/vomiting as intermittent infusion)</td><td></td></tr>
</table>

STAGE C. PALLIATIVE EXTUBATION PROCESS

Each PEx is unique and should be tailored to suit patient's and family's needs and comfort level.

Team Huddle	• Role assignment: Dedicate manpower for the following
	  • Doctors to oversee the process, titrate medications and document process
	  • Nurses to override alarms that cannot be switched off, suction and help with PEx
	  • MSW for psychosocial support
	• Simulate PEx process if possible (can be done the day prior to PEx).
	• Having the same physician and nurse remain with the patient for a period of time after PEx is advisable. This helps the family to remain calm and enables rapid adjustment of medications.

Prior to extubation	• Family involvement: Invite family to be present during PEx. They should be prepared about what they will witness. Explain end of life symptoms and that episodes of abnormal breathing, noisy breathing or involuntary movements do not necessarily imply suffering. • Decision to switch off monitors will depend on clinician assessment of possible outcome. Silent all alarms to help create a peaceful environment. • Remove restraints and unnecessary medical paraphernalia. • Adequate symptom control.
Extubation process	• Offer parents/caregivers to hold patient prior to PEx. • Quick and gentle ETT/oral suctioning if excessive secretions. • Turn off the ventilator. • Deflate ETT cuff, remove ETT and keep it covered with a towel. • Consider providing oxygen support via facemask or nasal cannula.This may partially relieve sensation of dyspnoea. • Provide tissues to family members to wipe off secretions/tears. Family should be encouraged to hold and touch patient. • Titrate medications for optimal symptom control.
Documentation	• Document time and date of PEx, all the steps during the extubation procedure, as well as the patient's progression immediately after extubation (instability, stability or death).

STAGE D. POST PALLIATIVE EXTUBATION

In the event of demise

- Offer to let family members help in last office/ cleaning of patient.
- Allow family members to spend time at the bedside/grief room (maximum 2 hours).
- Medical team to issue certificate of cause of death (for non-coroner's case).
- Explain death processes to family
  - Family to register the death within 24 hours.
  - Death can be registered at level 1 admission office (concierge) during office hours and at any police station out of office hours.
- List of funeral services can be found at nurses' counter.

If patient is stable post PEx

- Monitor symptoms and institute treatment in a timely manner.
- Continue monitoring respiratory rate and heart rate hourly.
- Consider putting back the monitor for ease of nursing care (with alarms silenced) if patient remains stable post PEx.
- Doctors to reassess clinical status at regular interval, or upon death.

Family support

- Continue communication with family throughout and after PEx. The availability of continuous psychological, social and spiritual support for the family, even after death, is recommended.

Staff support

- Multi-professional meetings/debriefing after PEx may help to address the emotional needs of staff through sharing of personal impressions of the process. Clear and respectful communication among staff may help to identify areas for improvement to optimise future PEx while sustaining their commitment and improving their emotional well-being (2).

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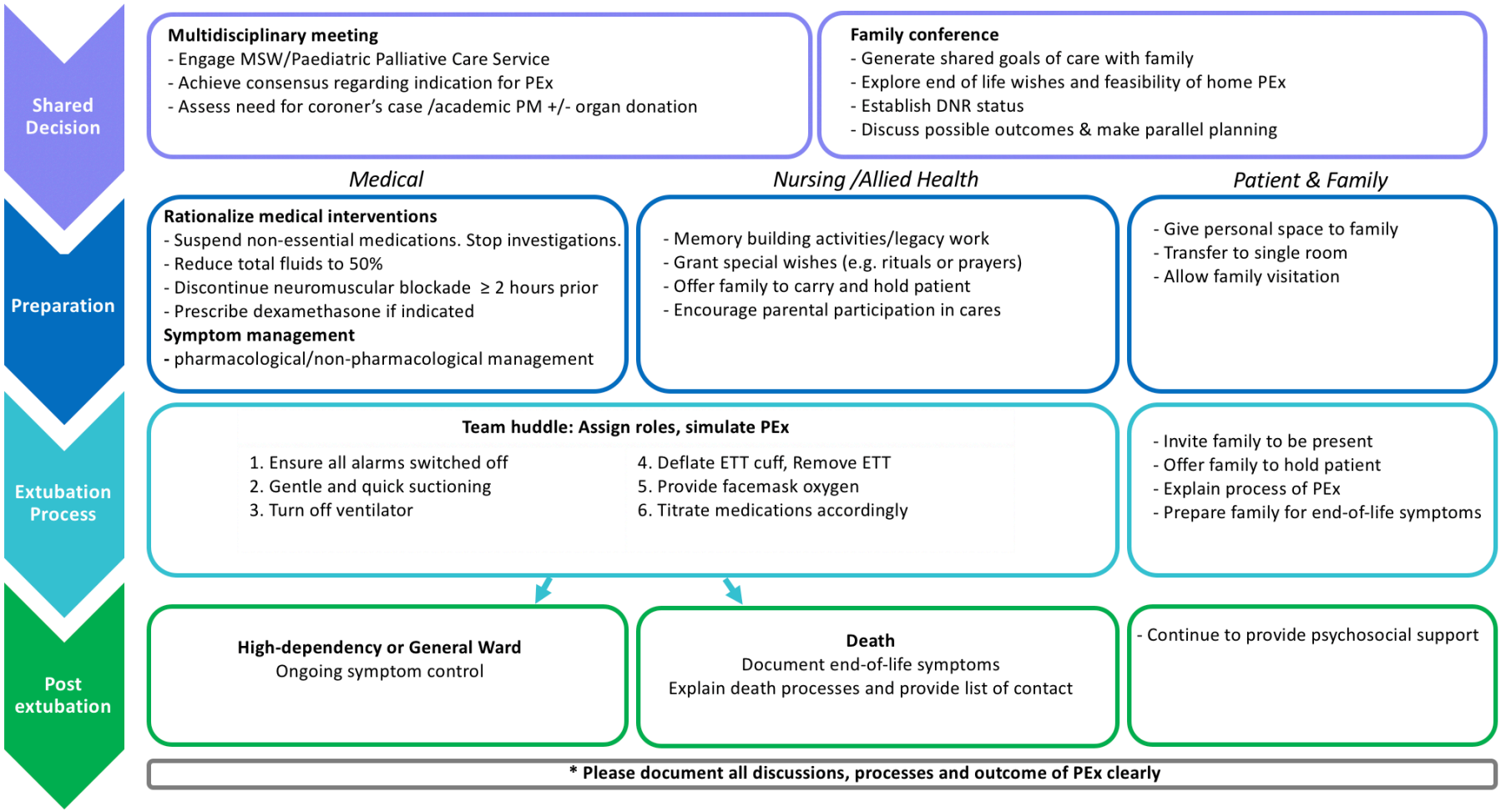
PALLIATIVE EXTUBATION (PEx) WORKFLOW



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