

NHS Lothian End of Life Care Guidance for Critical Care (Version 1 June 2023)

The purpose of this guideline is to support the provision of optimal end of life care (EoLC), in critical care, **after** a decision to withhold or withdraw life sustaining treatment (WLST) has been made.

The decision to WLST should be made by senior clinicians in accordance with Scots Law and best ethical and medical practice, as described in: GMC guidance *“Treatment and care towards the end of life”*, NHS Scotland *“Cardiopulmonary resuscitation decisions-integrated adult policy: guidance”* and FICM *“Care at the end of life”*. Once a decision has been made to proceed with WLST, and prior to more detailed WLST discussions with the family, organ and tissue donation should be considered and discussed with the relevant SNOD.

For patients where a decision has been made to proceed along the organ and tissue donation pathway, this guideline should be used in conjunction with that for the organ and tissue donation process.

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Part 1: Standard EoLC in Critical Care

Introduction

EoLC should always be tailored to the individual patient and their own circumstances.

WLST is the mode of death in 80% of patient who die in Critical Care. This may involve:

1. Discontinuation of invasive ventilatory support either by:
 - Extubation (most common)
 - Discontinuation of invasive ventilation with ETT (Endotracheal tube) in situ; consider when risk of airway soiling is very high e.g., active upper GI haemorrhage, small bowel obstruction.
2. Reduction in invasive ventilatory support, whilst the patient remains intubated e.g., where the patient is on multi-organ support.
3. Discontinuation of non-invasive ventilatory support e.g., CPAP, NIV or HFNO2.
4. Discontinuation of haemodynamic support, renal replacement therapy, invasive monitoring, and interventions.
5. Withholding any of the above.

Documentation

Minimum requirement:

Documentation of reasons for WLST, staff members involved and family discussion.

Please use relevant TRAK short code and canned text: /critcareeolcons

1. Completed DNACPR form and TEP (Treatment Escalation Plan).
2. Detailed plan for WLST with specific reference to:
 - Vasoactive medications
 - Renal replacement therapy
 - Other non-sedative medications that should be stopped/continued
 - Invasive monitoring and devices (e.g., ICP bolts and EVD)
 - Intravenous fluids and NG feeding
 - Plans for reduction/removal of ventilatory support (e.g., FiO2, reduction/discontinuation of mandatory breaths, Swedish nose via ETT)
 - Instructions for management of airway (e.g., extubation)
3. Symptom relief (including drug route and dosage. N.B. if a patient is likely to be discharged to the ward for EoLC, this must include a plan for SC symptom relief).
4. Plans for organ donation.
5. Specific considerations after death (e.g., cultural needs, cardiac post-mortem in SCD).

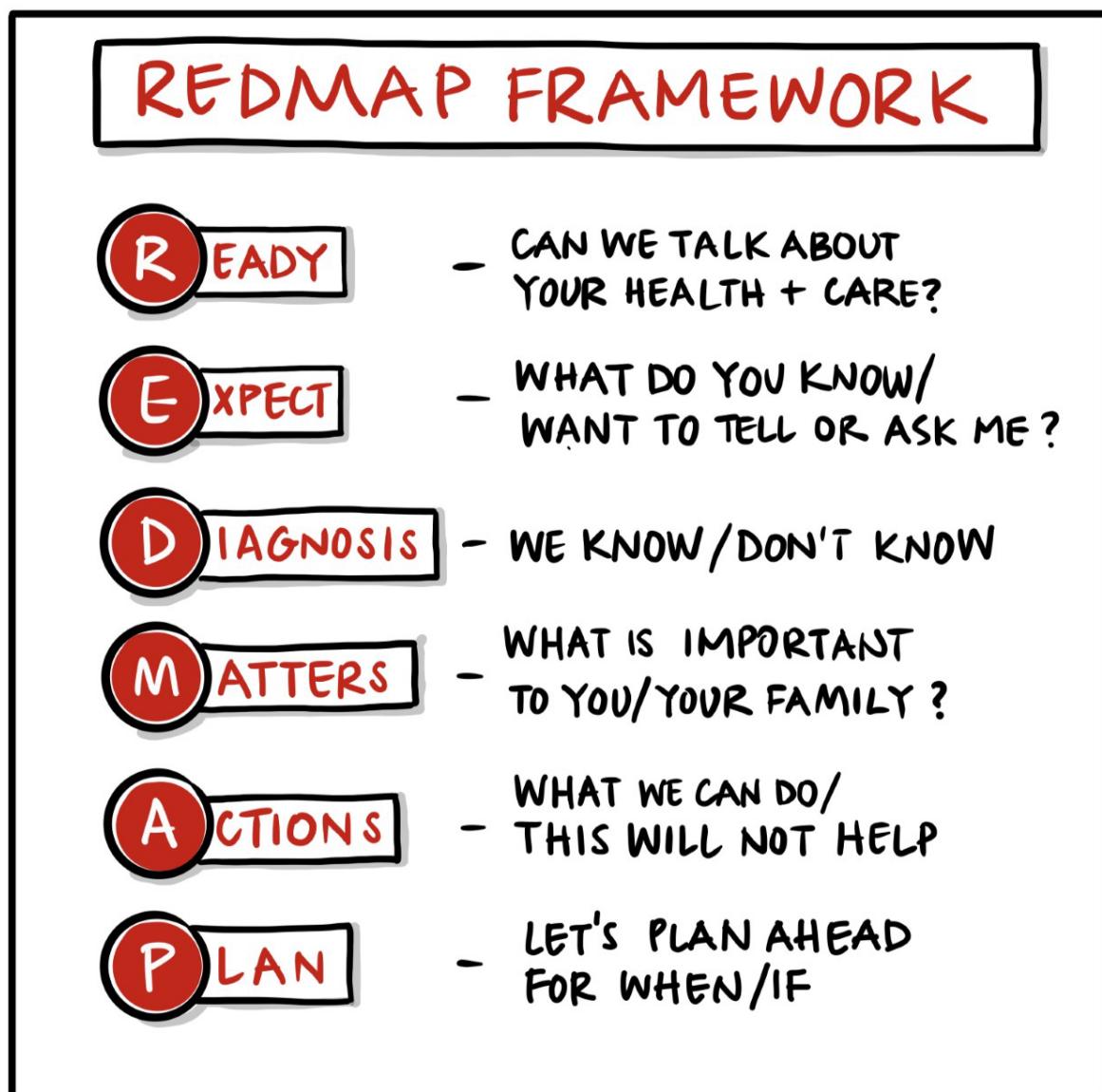
See also appendix I re considerations for withdrawal of organ support.

Family and pastoral support

It is vitally important to communicate effectively with patients (where they have capacity) and their families/relevant others, during each stage of the process. The REDMAP framework tool on the University of Edinburgh SPICT website (Supportive and Palliative Care Indicators Tool) is a useful resource to refer to: [REDMAP Framework – SPICT](#)

An updated version of REDMAP more directly applicable to critical care, is under development and will be added to this guideline in due course.

Figure 1: REDMAP framework



Identify patient's and family's cultural needs.

- The hospital chaplaincy service can be contacted through Switchboard and asking for the 'on-call chaplain'.
- A description of the variation in cultural practices at the end of life can be found [here](#)

Offer Critical care memory boxes (see also section G for memory boxes for bereaved children).

Offer NHS Lothian critical care bereavement follow-up and if applicable, please document consent to follow-up in the Trak notes, or follow-up diary and ensure NOK address obtained and recorded.

NHS Lothian bereavement services policies and guidance may be accessed [here](#)

Symptom relief

Most patients in critical care have established IV (Intravenous) access.

First line management in critical care will therefore usually be via IV opioids and anxiolytics unless:

- The patient has poor/no IV access.
- The patient is likely to be discharged to the ward for EoLC.
- There is a particular indication to provide SC (subcutaneous) medications e.g., use of syringe driver.

1. Analgesia

- i) IV opioids
- ii) SC opioids

a. IV opioids

Options include: IV alfentanil, or IV morphine.

Table 1. Continuing current rate of IV alfentanil

Pros	Cons
Patient's symptoms have already been stabilised on alfentanil. Low risk of inadvertent reduction in opioid dose.	Later conversion to SC morphine (e.g., if patient is likely to be discharged to the ward for EoLC) involves more complex dose adjustment
Preferable in patients with renal failure	May interact with other serotonergic agents
	Short half-life-i.e., shorter duration of effect with bolus doses (NB will wear off rapidly when stopped therefore when converting, ensure alternative analgesia has been established prior to cessation of infusion)
	Staff less familiar with use in EoLC

Table 2. Converting IV alfentanil to IV morphine

Pros	Cons
Staff more familiar with use in EoLC	Dose adjustment required (ideally establish adequate symptom control on IV morphine prior to WLST)
Straightforward dose conversion for SC regimen, including syringe driver	Risk of inadvertent reduction of opioid dosing

Useful information re dose equivalence can be found on the paindata.org site (ref 6)

N.B. dose conversion of IV alfentanil to IV morphine, to avoid inadvertent acute reduction of opioid
Alfentanil is more potent than morphine i.e., 1mg PO alfentanil =30mg PO morphine, or 1mg IV
alfentanil =5-10mg morphine IV (calculating equivalence is not straightforward due to
pharmacokinetic and pharmacodynamic factors; a dose equivalent of 1mg IV alfentanil: 5mg IV
morphine was used in the DESIST study and should be used as a starting point-see reference 7).

Not all patients require equivalent dosing for symptom relief e.g., patients where alfentanil has been up-titrated for ETT tolerance/cough suppression may no longer require an equivalent dose of opioid post extubation. Start at lower end of range (i.e., 1:5 equivalence) and titrate according to symptoms.

Table 3: Intravenous alfentanil to IV morphine equivalents

Alfentanil infusion rate 0.5mg/ml	Morphine infusion rate 2mg/ml
2mls/hr (1mg/hr)	2.5 mls/hr (5mg/hr)-5 mls/hr (10mg/hr)
4mls/hr (2mg/hr)	5mls/hr (10mg/hr)-10mls/hr (20mg/hr)

NB dose equivalence at higher doses is non-linear-*seek senior medical advice*

b. SC opioids

If the patient is being discharged to the ward for end-of-life care:

- Discuss with palliative care as soon as the decision to step down is made; it is essential that this referral is made **prior** to critical care discharge and allows enough time to allow IV to SC conversion. This includes cases not listed for discharge, but where a pre-emptive decision has been made to transfer a patient receiving EoLC care to the ward, if critical care capacity issues arise.
- **IV opioids must be converted to SC opioids prior to ward step down.** This may involve down-titration of the equivalent dose used, whilst the patient was intubated. **A patient must never be discharged to the ward for EoLC on IV opioids or sedatives.**
- When using a syringe driver, a patient should be established on a syringe driver in Critical Care, prior to transfer.

There may also be certain situations in Critical Care, where a SC syringe driver is preferable e.g., breathless patients in a level 2 area, or patients with no CVP line in situ.

Syringe driver options in Critical Care include:

1. SC morphine syringe driver (most common)
2. SC alfentanil (for specific indications and if advised by senior clinicians)-see prescribing advice in attached link
<https://www.palliativecareguidelines.scot.nhs.uk/guidelines/medicine-information-sheets/alfentanil.aspx>

See also: <https://www.palliativecareguidelines.scot.nhs.uk/guidelines/end-of-life-care/syringe-pumps>

2. Sedation

For extubated, spontaneously breathing patients, or those with an ETT in situ who have been removed from ventilatory support:

- Propofol should be converted to IV midazolam.
- The patient should be established on IV midazolam, prior to extubation.
IV midazolam 1mg/ml at 1-10ml/hr (clinician to specify dose range)

For patients who remain intubated and ventilated (e.g., those in refractory multi-organ failure on high dose vasoactive medications):

- Continue current sedation and titrate as required.

For all patients on alpha 2 agonists:

- Alpha 2 agonists e.g., dexmedetomidine and Clonidine can be continued for all patients and should not be abruptly discontinued after long term use. Reduce infusion rate slowly or consider conversion to NG if ward step down planned, as IV infusions cannot be administered on a ward and no SC route available. Clarify plan with senior treating ICU clinician.

3. Other anticipatory care medicines

Ensure appropriate anticipatory medicines are prescribed as per below:

<https://www.palliativecareguidelines.scot.nhs.uk/guidelines/pain/Anticipatory-Prescribing.aspx>

Where advice is required on dosing, please contact palliative care.

Withdrawal of life sustaining treatment

Monitoring and preparing the environment.

- Turn off beside patient monitoring and set to nursing station view.
- Silence alarms on bedside monitor
- Set to privacy/nursing station view and switch off bedside monitor.
- Remove all non-essential equipment.
- Lower bed and cot sides
- Provide chairs and tissues.
- Ensure curtains are closed and apply thistle sign to outside of curtains
- Consider move to cubicle, if available

N.B. some amendments may be required in patients proceeding to DCD donation; the duty SNOD will advise.

Instructions for prescribed medications

Drugs not required for symptom control, should ordinarily be discontinued (seek advice from medical staff)

The following medications should be continued (unless advised otherwise, by senior medical staff)

- IV anticonvulsants in patients with status epilepticus/poorly controlled seizures
- Medications for drug and alcohol withdrawal
- Sedation, analgesia, antipsychotics

Nutritional support and IV fluids

These should ordinarily be discontinued (they provide no symptom relief), however family members should be specifically informed that this is being done.

NG nutrition should ideally be stopped as soon as possible after a decision to proceed with palliative extubation has been made (to decrease the risk of vomiting post extubation)

Withdrawal of invasive ventilation

Palliative extubation

- Ensure medical staff have fully documented plan in medical notes
- Ensure family understand the process.
 - Explain that airway obstruction, airway noises and airway soiling (secretions or vomitus) may occur and provide reassurance that the patient will be unaware of this and not distressed.
- Stop NG feed, ideally 4 hrs pre-extubation, (but this should not delay extubation if this has not been performed)
- Attempt to establish on spontaneous mode of invasive ventilation
- Reduce FiO₂ to 0.21
- Establish appropriate analgesia and sedation regimen and ensure symptom relief is adequate prior to extubation.
- Consider antisialogogue (i.e., drugs which decrease saliva/secretion production) prior to extubation e.g. buscopan
- Aspirate NG tube immediately prior to extubation
- Perform endotracheal and oropharyngeal suction
- If family wish to leave (majority of cases), ask them to wait outside
- Turn off ventilator and monitor alarms
- Extubate (ensure oropharyngeal suction is to hand)
- If significant mechanical airway obstruction then nurse the patient onto their side with head of the bed up and the chin tilted slightly upwards.

Discontinuation of ventilation with ET tube in situ (consider when risk of airway soiling is v high e.g. active upper GI haemorrhage, small bowel obstruction)

- As per initial pre-extubation steps above
- Discontinue ventilator support and disconnect ventilator.

Consider use of Swedish nose with no tubing, to avoid an open-ended ET tube, as some families find this distressing.

Reduction in ventilatory support, whilst the patient remains intubated e.g., where the patient is on multi-organ support

- Ensure family understand the process (families usually prefer to remain present in this circumstance and death may be very rapid).
- Turn-off apnoea ventilation and alarms.
- Withdraw other forms of organ support.
- Decrease ventilatory support as directed by clinicians e.g., FiO₂ of 0.21

Withdrawal of cardiovascular support

- Ensure family understand the process (as above).
- Discontinue vasoactive drugs, there is no requirement to wean these unless specifically directed by the senior ICU clinician.
- Intra-aortic balloon pump (IABP). If an IABP is in-situ, the pump can be stopped and turned off (leave IABP in situ until after death, but remove prior to transfer to mortuary).

Management of pacemakers and Cardiac Implantable Electronic Devices (CIED)

a) Temporary transvenous pacing wire (TPW)

Stop transvenous pacing and turn pacing box off (the pacing box can be disconnected). Leave TPW in situ until after death but remove **prior** to transfer to the mortuary.

b) Pacemaker without defibrillation functionality

A pacemaker without defibrillation functionality is unlikely to need any intervention in the EOL period as the terminal rhythm is likely to be a ventricular arrhythmia and therefore unaffected by the pacemaker function.

A magnet should not be used to attempt to deactivate a pacemaker **without** defibrillation functionality, as this will place the pacemaker into a fixed pacing mode.

If a pacemaker without defibrillation functionality requires to be switched off, this should be done by the cardiac electrophysiology department or cardiology team (this is sometimes considered in DCD organ donation and should be discussed with the SNOD).

c) Implantable cardiac defibrillator (ICD)

If an ICD is in-situ this will require to have its defibrillator function switched off for WLST as it will deliver defibrillation at the onset of VT/VF, which will prolong the end-of-life process and be distressing for both the patient and next of kin.

This can be done by the cardiac electrophysiology department or cardiology team, or an appropriate magnet can be used to deactivate the defibrillation function by placing it over the device (and securing with tape).

Detailed guidance from the Resuscitation Council UK is available [here](#)

N.B. Guidance on management of Cardiac Implantable Electronic Devices after *death*.

The presence of CIED should be notified to the mortuary and managed as per the NHS

Lothian guidance [here](#)

This guidance also applies to other implantable devices such as Sacral nerve stimulators, baclofen pumps and programmable hydrocephalus shunts.

Ongoing patient review

Patients receiving EoLC do not ordinarily require a full daily review, however **regular clinician review is extremely important**, with appropriate documentation, to ensure:

- The provision of adequate symptom relief.
- Assessment of any changes in the patient's condition.
- Adjustment of analgesia and sedation regimens where necessary.
- Adequate management of more complex EoLC circumstances (as listed in the next section).
- Plans for discharge from Critical Care if necessary.

When to refer to palliative care

Palliative care input has a vitally important role to play in EoLC in critical care. **Early** discussion with the palliative care team is beneficial, especially in the following circumstances:

- Planned/likely step down to the ward for EoLC
- Complex cases
- Refractory seizures
- Planned withdrawal of longer-term respiratory support
- Any situation where EoLC advice is needed

Contact details

- RIE: Extension 21993, bleep 5715, out of hours via switchboard
- WGH: Bleep 8174 (Mon-Fri 9am-5pm)
- SJH: Bleep 3833 (Mon-Fri 9am-5pm)
- Submit a TRAK referral after bleeping.
- Medical Advice out of hours (5pm-9am/weekends) via switchboard

After Death

Complete relevant paperwork (**please ensure an e mail address from the family/relevant other has been obtained and recorded on the death notification paperwork**) as per NHS Lothian Crit Care guidance: [Microsoft Word - Documentation and procedures following death_draft2_2018GM.docx.pdf \(scot.nhs.uk\)](https://www.scot.nhs.uk/documents/2018GM/death_draft2_2018GM.docx.pdf)

Medical staff to complete MCCD as per Scotland's CMO guidance: [CMO Letterhead.dot \(scot.nhs.uk\)](https://www.scot.nhs.uk/documents/2018GM/CMO_Letterhead.dot)

Financial support services for families after death:

<https://services.nhslothian.scot/bereavementservice/support-services/>

<https://www.mygov.scot/funeral-support-payment>

<https://www.mygov.scot/bereavement-benefits>

Genetic testing post OOHCA

Some deaths following OOHCA are due to inherited cardiac causes

If the patient fulfils the criteria below, then genetic testing should be considered.

- Deaths in general critical care following OOHCA
- Adults under 60
- Without clear evidence of IHD/chronic coronary artery disease (CAD)
- Without clear evidence of non-cardiac precipitant
- With sufficient information to complete the MCCD

Further information is available here (NHS Lothian Critical Care guideline following Sudden Cardiac Death where death occurs in ICU: [link to be inserted for new guideline written by Tom Craven](#))

Part 2: Managing EoLC care in specific circumstances.

There are several situations in critical care where EoLC may be particularly challenging. These include:

- A. Management of symptomatic airway obstruction (especially after palliative extubation)
- B. Refractory status epilepticus/myoclonus
- C. Symptomatic breathlessness-often more of an issue in L2 patients
- D. Secretion management
- E. Vomiting post extubation (i.e., how to minimise risks and manage it, when it occurs)
- F. Cessation of HFNO2 in the awake patient
- G. WLST in patients with young children

A) Management of symptomatic airway obstruction after palliative extubation

Some groups of patients, particularly younger patients with a hypoxic brain injury and preserved brain stem function, may develop airway obstruction after a palliative extubation.

This can be very distressing for families and staff members. Prior to a planned palliative extubation, counsel families that an obstructed breathing pattern may occur, including what it may sound and look like. It is helpful for families to hear that although it may sound distressing for them, it represents a normal part the dying process for the patient and the patient is not suffering.

The risk can be diminished by ensuring adequate preparation prior to extubation (see above) with particular attention to ensuring sedative and analgesic regimens have been optimised.

If significant features of **symptomatic airway obstruction** develop, the following approach should be adopted:

- Reassure family members that:
 - the patient is unaware and not suffering.
 - It is a normal and expected part of the dying process.
- Ensure adequate titration of sedation and analgesia (bolus doses may be required)
- If respiratory secretions are contributing, consider the need for anti-muscarinic drugs to reduce secretion burden – see secretion management section (table 5) and provide adequate suction.
- Consider repositioning the patient e.g., on their side.
- **Avoid the use of airway adjuncts** as they can cause pharyngeal stimulation which can lead to vomiting and may contribute to patient distress.
- Seek advice from senior medical staff.

If there are features of **delirium and/or terminal restlessness**, consider:

Table 4: pharmacological management of terminal restlessness

Drug	Dose	Comments
IV haloperidol	1.25-2.5mg IV 2hourly (max 15mg/24hrs, reduce dose by 50% in the elderly).	Consider switch to levomepromazine if repeated doses or cumulative dose >5mg required.
SC levomepromazine	10-25mg SC 2 hourly as needed. Use lower doses (5mg 2 hourly) if frail.	Avoid in patients with seizures. Longer duration of action than haloperidol-less frequent administration required.

Both drugs are antipsychotics of the phenothiazine class. They may cause anticholinergic (e.g., dry mouth) and extrapyramidal (e.g., abnormal movements) effects. Both have antihistamine and anti-emetic properties.

B) Refractory status epilepticus/myoclonus

Early involvement of palliative care is important in patients with problematic refractory seizures at the end of life, especially in the following circumstances:

- planned palliative extubation with difficult seizure control and predicted prolonged time to asystole.
- Patients who are likely to be stepped down to the ward for EoLC.

<https://www.palliativecareguidelines.scot.nhs.uk/guidelines/palliative-emergencies/Seizures.aspx>

Key points to consider:

- For this group of patients, it is important that sedation which has anticonvulsant action e.g., propofol, is not abruptly discontinued/reduced.
- All IV anticonvulsant therapy should be continued (unless advised otherwise by senior medical staff, or SC conversion planned for ward step down)
- It may be preferable to continue IV propofol and keep the patient ventilated (N.B. in this circumstance propofol can also be continued post extubation as an anticonvulsant, under consultant direction)
- If weaning/ceasing propofol, ensure adequate seizure control is achieved on IV midazolam and optimal IV anticonvulsants, **prior** to extubation.
- For patients who are being discharged to the ward SC anticonvulsants may be required, as per NHS Scotland palliative care guidelines above. These patients must be referred to palliative care and established on SC treatment, prior to step down (allow adequate time for this).

C) Symptomatic breathlessness

This is often more of an issue in L2 patients.

If there are features of delirium and/or terminal restlessness, consider pharmacological management as per table 4 above:

Awake patients can self-report breathlessness. For those unable to report symptoms, the Respiratory Distress Observation Scale (RDOS) is a validated tool to assess for symptomatic breathlessness in dying patients (Ref 8). A score of < 4 generally indicates no or mild distress, 4-6 indicates moderate distress, and a score of >7 indicates severe distress. The RDOS score can be used to assist titration of symptom relief and assess response.

Figure 2: RDOS tool

Variable	0 points	1 point	2 points	Total
Heart rate, beats per minute	<90	91-109	≥110	
Respiratory rate, breaths per minute	≤18	19-30	>30	
Restlessness: nonpurposeful movements	None	Occasional, slight movements	Frequent movements	
Accessory muscle use: rise in clavicle during inspiration	None	Slight rise	Pronounced rise	
Paradoxical breathing: abdomen moves in on inspiration	None		Present	
Grunting at end expiration: guttural sound	None		Present	
Nasal flaring: involuntary movement of nares	None		Present	
Look of fear	None		Eyes wide open, facial muscles tense, brow furrowed, mouth open	
Total				

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Non-pharmacological management of breathlessness

- Positioning – sit upright.
- Provide airflow (patients may find a fan useful)

Table 5: Pharmacological management of breathlessness

Opioid (first line management)	Benzodiazepines (less effective than opiates for breathlessness, second line)
Morphine 2-5mg SC or 1-2mg IV, repeated hourly as needed. Dose can be incremented by 30-50% if needed	Midazolam 2-5mg SC or 1-2mg IV, repeated hourly as needed
Levomepromazine (for terminal distress despite opiates and benzodiazepines)	
10-25mg SC 2 hourly as needed. Use lower doses (5mg 2 hourly) if frail.	

N.B. dose adjustment may be required dependent on background opioid or benzodiazepine dose, in which case seek senior advice.

See also NHS Scotland palliative care guidance for COVID-19 lung disease which describes symptomatic management of air hunger (also useful for non-COVID-19 situations, where a patient is experiencing air hunger)

[Scottish Palliative Care Guidelines - End of Life Care Guidance when a Person is Imminently Dying from COVID-19 lung disease](#)

D) Secretion management

During the dying phase of a person's illness, airway secretions may accumulate and result in gurgling and rattling noises during inspiration and expiration. Often, noisy secretions and breathing can prove to be distressing to families and carers.

Key points to consider:

- When discussing symptoms that may occur during the dying phase with patients and families, it may be useful to explain prior to a planned WLST that such noises may occur, and that generally a semi-conscious or unconscious patient will not be distressed by the noises.
- Stop feed and additional fluid sources to reduce the risk of fluid overload during the dying process.
- In managing significant secretions, it can be useful to position the patient onto their side with their head elevated to encourage postural drainage.
- If positioning fails to improve secretion burden, an anti-muscarinic drug can be considered as per palliative care guidance, to reduce secretion production.

Table 6: pharmacological management of secretions

Drug	Initial dosing	Time interval to assess initial response	Dosing Interval
Hyoscine butylbromide	20 mg subcutaneously	20-30 minutes	1 hourly as required Maximum 120mg in 24 hours
Glycopyrronium bromide	200 to 400 micrograms subcutaneously	30-60 minutes	4 Hourly as required (can be increased to hourly on palliative care advice)

E) Vomiting post extubation

As there may be several potential contributory factors, the management of vomiting post extubation can be challenging. It is important to minimise risks and warn families where the risk is high e.g.: patients with ileus, GI bleeding, bowel obstruction, constipation and high NG aspirates/poor NGT absorption.

Non-pharmacological management

- NG feed should be stopped and NG Tubes (NGT) aspirated prior to a palliative extubation.
- In patients who have not been absorbing feed with high gastric aspirates, or in those with mechanical obstruction, it may be useful to leave the NGT in situ over the dying process to allow for symptomatic aspiration/free drainage of the NGT.

- Constipation is a common cause of vomiting. Ideally, take preventative action and ensure that NHS Lothian Critical Care guidelines for treatment of constipation are adhered to.

Pharmacological management

- Levomepromazine and haloperidol are highly effective antiemetics and can be useful in a dual role in this situation (same doses as for sedation, table 4). Standard anti-emetics e.g., ondansetron may be less useful.
- Pharmacological management of vomiting post extubation should be guided by assessment of the potential clinical contributors as detailed above.

F) Withdrawal of HFNO2, CPAP or NIV in the awake patient

Withdrawal of respiratory support in the awake patient poses several challenges and requires senior input; patients can develop a degree of psychological dependence on HFNO2, or other forms of non-invasive respiratory support.

Literature suggests there is a poor relationship between oxygen saturation levels and reported levels of dyspnoea in dying patients. Explain this to the patient, alongside explaining to them that it's unlikely they will need oxygen during the dying phase of their illness, and instead the focus will be on symptomatic relief of dyspnoea and distress.

There are pros and cons to gradual reduction of respiratory support. Once adequate symptom relief has been achieved, stepwise weaning is not encouraged as it may increase patient anxiety.

Refer to guidance in section C, above and titrate opiates and anxiolytics in accordance with RDOS tool (figure 2, page 13).

Early involvement of palliative care is especially important in complex situations and for patients who have been on respiratory support for longer time periods e.g., patients with MND. These patients require a tailored approach.

References **9** and **10** may be useful resources for this situation.

G) WLST in patients with young children

Preparing children for the death of a relative or someone close to them can be a difficult thing to do. Families may ask for advice about the best way to tell a child that their loved one is dying, and you may be asked to participate in those conversations with children.

Children may wish to be involved in memory making activities prior to a planned WLST (see below)

NHS Lothian support options:

RHCYP chaplain and bereavement service: Ext 50168 or via switchboard

Telling children their loved one is dying:

- Be honest and open with them – don't shield them from the truth.

- Recognise that you may need to give information in smaller chunks, rather than all at once.
- You may need to repeat messages several times to allow children to fully appreciate what you have told them.
- Ask them to tell you about their loved one – what are they like, what are their favourite memories of the person?
- Use clear, age-appropriate language – use terms like “die” and avoid ambiguous terms like “pass away”. Avoid talking about “going to sleep” as children may then be worried about going to sleep themselves.
- Be aware of children overhearing other conversations you’ve had with adults. Make sure you check their understanding and give them the opportunity to ask questions.
- Be prepared to answer questions about what happens to the body after someone dies.

See also Appendix II below, for full list of children’s bereavement services.

Table 7: communication with children of different ages

Young Children (< 5 years)	Older children (6-12 years)	Teenagers
<ul style="list-style-type: none"> • Let them know the illness is not their fault. • Reassure them that they/other relatives cannot catch the illness. • Utilise age-appropriate resources in child bereavement box. 	<ul style="list-style-type: none"> • Emphasise the loved one cannot come back after death. • Let them know it's ok to be sad, but it's also ok to still have fun and play. • Use age-appropriate resources and involve them in memory making activities. 	<ul style="list-style-type: none"> • May find it more difficult than younger children, as they can appreciate the gravity of the loss. • Emphasise there is no right or wrong way to feel. • Give them time and space to themselves when they want it. • Tell them about useful sources of information and support as below. • Memory making if want to engage. • Encourage care givers to maintain normal rules and boundaries.

Bereavement/ Memory Making boxes

As a result of an NHS Lothian charity grant, we have been able to put together bereavement boxes for the children (<16 years) of patients who die in ward 118 (see picture below). These are kept within the reception area (a small no. of boxes have also been sent to the WGH and SJH and can be replaced when used). These contain written resources, books and activities recommended by child

bereavement experts, handprint resources, "forget me not" seeds, a small soft toy, and a jewellery memory making activity, in addition to signposting to bereavement support groups and options. These boxes are **age-specific** and are labelled as so. **Please do not open/make use of these resources out with the setting of supporting bereaved children, as we need to evidence their benefit for ongoing NHS Lothian charity support.**

Figure 3: Pictures of memory box and contents for children



References

- 1) GMC guidance: <https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life/guidance>
- 2) FICM guidance: <https://www.ficm.ac.uk/standardssafetyguidelinescriticalfutures/care-at-the-end-of-life>
- 3) NHS Scotland DNACPR policy: <https://www.gov.scot/publications/attempt-cardiopulmonary-resuscitation-dnacpr-integrated-adult-policy-decision-making-communication/>
- 4) [Scottish Palliative Care Guidelines](#)
- 5) NICE Guidance: Care of dying adults in the last days of life: <https://www.nice.org.uk/guidance/ng31> -
- 6) West of Scotland pain management group opioid calculator: <https://paindata.org/calculator.php?dothis=reset>
- 7) DESIST study: <https://bmjopen.bmj.com/content/bmjopen/6/3/e010148.full.pdf>
- 8) Campbell ML, Templin T, Walch J. A Respiratory Distress Observation Scale for patients unable to self-report dyspnea. *J Palliat Med*. 2010 Mar;13(3):285-90. doi: 10.1089/jpm.2009.0229. PMID: 20078243. <https://www.liebertpub.com/doi/10.1089/jpm.2009.0229>
- 9) "Withdrawal of Assisted Ventilation at the Request of a Patient with Motor Neurone Disease: Guidance for Professionals" Association for Palliative Medicine of Great Britain and Ireland, 2015 https://apmonline.org/wp-content/uploads/2018/11/2018-guidance-on-withdrawal-of-assisted-ventilation_final-4.pdf
- 10) West Midlands Specialist Palliative Audit and Guideline Group "Withdrawal of assisted ventilation for hospital inpatients outside of critical care settings/ICU" <https://www.westmidspallcare.co.uk/wp-content/uploads/Assisted-ventilation-withdrawal-in-hospital-front-sheet.pdf>
- 11) [Dying with Dignity in the Intensive Care Unit | NEJM](#)

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Appendix I: Considerations in withdrawal of life support (NEJM)



Table 4. Considerations and Cautions in the Withdrawal of Life Support.*

Variable	Considerations	Cautions
Discontinuation of renal-replacement therapy	Confers a low risk of physical distress	Death may take several days if this is the only advanced life support withdrawn
Discontinuation of inotropes or vasopressors	Confers no risk of physical distress Death may occur quickly if the patient requires high doses, with or without withdrawal of mechanical ventilation	Death may not occur quickly if the patient requires low doses, particularly if mechanical ventilation is ongoing
Weaning from inotropes or vasopressors	Confers no risk of physical distress	May prolong the dying process, particularly if the patient requires low doses and this is the only life support withdrawn
Discontinuation of mechanical ventilation	Confers risk of dyspnea Death may occur quickly if the patient requires high pressure settings or high oxygen levels	Preemptive sedation is typically needed to blunt air hunger due to rapid changes in mechanical ventilation Death may not occur quickly if the patient requires low pressure settings or low oxygen levels
Weaning from mechanical ventilation	Confers low risk of dyspnea	May prolong the dying process, particularly if the patient requires low pressure settings or low oxygen levels and this is the only life support withdrawn
Extubation	Confers risk of dyspnea Avoids discomfort and suctioning of endotracheal tube Can facilitate oral communication Allows for the most natural appearance	Informing families about possible physical signs after extubation can prepare and reassure them Secretions may cause noisy breathing, which may be reduced with the use of glycopyrrolate; the use of glucocorticoids may reduce stridor Airway obstruction may occur; jaw thrust or repositioning of the patient may help Not advised if the patient has hemoptysis

* The choice regarding the type and dose of medications depends on prevailing levels of analgesia and sedation at the time of the decision, the mode and sequence of the planned withholding or withdrawal of life support, and myriad other factors.⁴² These factors preclude any specific dose recommendations. Physician availability for the family during the dying process is as important as individualized adjustment of medication.

[Dying with Dignity in the Intensive Care Unit | NEJM](#)

Appendix II Bereavement Support for Children and Young People

ChildLine: available to help anyone under the age of 19, in the UK, with any distressing issues that they are going through. One-to-one counsellor chats available online.

Helpline: **0800 11 11** (24 hours a day, every day) Email: email from your locker. (?check what this means)

Website: <https://www.childline.org.uk>

Child Bereavement UK A national charity providing support for bereaved families, children and professionals. This organisation helps **children, young people**, parents and families to rebuild their lives when a child dies.

Tel: **0800 028 8840** (Monday-Friday 9am-

5pm) Email: helpline@childbereavementuk.org & scotlandsupport@childbereavementuk.org

Website: <https://www.childbereavementuk.org>

Winston's Wish

A national charity providing support for bereaved children and young people.

Helpline: **08088 020 021** (Monday-Friday 9am-5pm ~ closed bank holidays ~ voicemail service available) General Enquiries: **01242 515 157**

Email: ask@winstonswish.org

Website: <https://www.winstonswish.org>

Richmond's Hope: This charity provides support for bereaved children and young people from the age of 4-18 years old. Based in **Edinburgh, The Lothians, The Borders & Glasgow**.

Tel: **0131 661 6818** (Monday-Friday 9am-5pm)

Email: info@richmondshope.org.uk

Website: <https://www.richmondshope.org.uk>

Hope Again: Hope Again is the youth website of [Cruse Bereavement Care](#). It is a safe place, where young people who are facing grief can share their stories with others.

Helpline: **0808 808 1677** (Monday-Friday 9.30am-5pm) General Enquiries: **020 8939 9530**

Email: hopeagain@cruse.org.uk

Website: <http://www.hopeagain.org.uk>

Team Jak Foundation: Based in **Livingston**, this foundation supports children and young people with cancer, their families, friends and those bereaved.

Tel: **01506 412 302** (Monday-Friday 9am-5pm)

Email: info@teamjak.org.uk

Website: <https://www.teamjak.org.uk>

Grief Matters; A bereavement service, based within West Lothian Drug and Alcohol Service, for young people aged 12-18 years, who live in **West Lothian** and who have been affected by an unexpected death (the bereavement does not need to be substance related).

Tel: **01506 430 225** (Monday-Friday 9am-5pm)

Email: enquiries@wldas.org

Website: <http://www.wldas.com>