Guidance for Withdrawal of Life Support and End of Life Care

Intensive Care Unit Raigmore Hospital

The following have been completed:

□ The multiprofessional team has agreed that the patient is dying.

□ The referring team has agreed that the patient is dying and the referring Consultant is informed of the change to palliative care.

□ Procurator Fiscal is informed Yes □ N/A □

□ Family/other aware that the planned care is now focused on the care of the dying. Family meeting is documented in the clinical record.

□ DNACPR form is completed.

□ Adult Incapacity form is completed.

□ Specialist Nurse in Organ Donation is informed of the change to palliative care.

□ Any implantable cardioverter defibrillator is deactivated Yes □ No □

□ The patient will be assessed regularly and a formal multidisciplinary team review will be undertaken every 24 hrs.

Unless otherwise specified by the ICU Consultant, the following will be discontinued:

- Bedside monitoring is changed to 'visitors screen'.
- Recording of routine vital signs.
- All investigations and tests including blood tests and glucose monitoring.
- All DVT prophylaxis i.e. pharmacologic therapies, intermittent compression device, compression stockings.
- IV antibiotics, iv fluids, enteral or total parenteral nutrition, renal replacement therapy.
- When patient appears comfortable, decrease O2 therapy to 21%, discontinue ventilation and extubate.
- Stop vasoactive infusions immediately after extubation.

Medication instructions – initiate sedative/analgesic infusions:

- Continuous iv infusion(s) of: _____ refer to guidance on page 2.
- Subcutaneous administration of: _____ refer to guidance on page 2.
- Stop paralysing agents Yes □ N/A □

Authorisation to proceed to withdrawal of life support and commence end of life care:

Patient's name: _____	ICU Consultant (print name): _____
Date of birth: _____ Age: _____	ICU Consultant's signature: _____
CHI/unit number: _____	Date: _____ Time: _____

Guidance For Palliative Care Continuous Intravenous Infusions

Drug	Concentration	Suggested starting dose	Bolus dose
Morphine 50mg in 50ml 0.9%sodium chloride	1mg/ml	Start infusion 2 to 10mg/hr and titrate to patient comfort	1mg bolus increment PRN
Midazolam 50mg in 50ml 0.9%sodium chloride	1mg/ml	Start infusion 2 to 10mg/hr and titrate to patient comfort	1mg bolus increment PRN
Propofol 500mg in 50ml	10mg/ml	Start infusion 50mg to 200mg/hr and titrate to patient comfort	10mg bolus increment PRN
Diamorphine 50mg in 50ml 0.9%sodium chloride	1mg/ml	Start infusion 2 to 10mg/hr and titrate to patient comfort	1mg bolus increment PRN

Managing patient discomfort:

- Morphine is the preferred choice of opioid for the intravenous route as per palliative care guidelines.
- If the patient is already receiving an alternative opioid - continue to use rather than switch.
- Medicines for symptom control should only be given when needed, at the right time and just enough and no more than is needed. This should be titrated as per individual patient need. The most important concept is that no ceiling is placed on dosage if the goal of receiving patient distress has not been achieved.
- PRN prescriptions for analgesics and sedatives should include the indication for administration e.g. “if required for pain, anxiety, acute agitation, restlessness or shortness of breath”.
- Increases in dosage should be preceded by a bolus so that steady-state levels are rapidly achieved. Bolus doses should be titrated in small increments. Nursing staff must document the rationale for bolus administration/escalating doses of palliative medications.
- Conversion for iv diamorphine to iv morphine: diamorphine 1mg = 1.5mg morphine, diamorphine 2mg = 3mg morphine, diamorphine 5mg = 7.5mg morphine and diamorphine 10mg = 15mg morphine.

Guidance For Using The Subcutaneous Route During Palliative Care

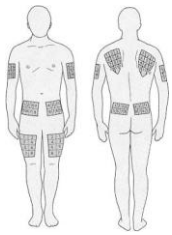
Consider subcutaneous route as appropriate and where iv route is not available. Subcutaneous infusion may be administered as a continuous delivery or intermittent bolus via a subcutaneous cannula. Check the infusion site for redness, swelling, leakage of fluid or discomfort/pain.

Diamorphine is the preferred opioid choice for the subcutaneous route and may be administered as:

1. A continuous infusion: suggest starting at 1 to 5mg/hr and titrate to patient comfort.
2. Bolus method: a more concentrated preparation may be used e.g. 5mg/ml or 10mg/ml

Suitable sites for subcutaneous cannula:

- Anterior aspect of the upper arm or anterior abdominal wall.
- Anterior chest wall.
- Anterior aspect of thigh.
- The scapula may be considered for agitated or delirious patients who may pull on the line.



Avoid the following sites:

- Broken skin.
- Bony prominences.
- Irradiated sites.
- Skin folds.
- Oedematous areas or lymphoedematous areas.

The Critical-Care Pain Observation Tool (Gelinas et al., 2006)

Indicator	Description	Score	
Facial expression	No muscular tension observed	Relaxed, neutral	0
	Presence of frowning, brow lowering, orbit tightening, and levator contraction	Tense	1
	All of the above facial movements plus eyelid tightly closed	Grimacing	2
Body movements	Does not move at all (does not necessarily mean absence of pain)	Absence of movements	0
	Slow, cautious movements, touching or rubbing the pain site, seeking attention through movements	Protection	1
	Pulling tube, attempting to sit up, moving limbs/ thrashing, not following commands, striking at staff, trying to climb out of bed	Restlessness	2
Muscle tension Evaluation by passive flexion and extension of upper extremities	No resistance to passive movements	Relaxed	0
	Resistance to passive movements	Tense, rigid	1
	Strong resistance to passive movements, inability to complete them	Very tense or rigid	2
Compliance with the ventilator (intubated patients)	Alarms not activated, easy ventilation	Tolerating ventilator or movement	0
	Alarms stop spontaneously	Coughing but tolerating	1
OR	Asynchrony: blocking ventilation, alarms frequently activated	Fighting ventilator	2
Vocalization (extubated patients)	Talking in normal tone or no sound	Talking in normal tone or no sound	0
	Sighing, moaning	Sighing, moaning	1
	Crying out, sobbing	Crying out, sobbing	2
Total, range			0-8

How to use the Critical-Care Pain Observation Tool (CPOT):

1. The patient must be observed at rest for 1 minute to obtain a baseline value of the CPOT.

2. The patient should be observed during nociceptive procedures (e.g. turning, endotracheal suctioning, wound care, dressing changes) to detect any change in the patient's behaviours to pain.

3. The patient should be evaluated before and at the peak of an analgesic to assess if the treatment was effective in relieving pain.

4. For the rating of the CPOT, the patient should be attributed the highest score observed during this period.

5. The patient should be attributed a score for each behaviour within the CPOT and muscle tension should always be evaluated last especially when the patient is at rest because just the stimulation of touch (passive extension and flexion of the arm) may lead to behavioural reactions.

6. Pain should be reassessed after procedures have been completed – this should be done after 20 minutes of completing the procedure.

Guidance For Withdrawing Supportive Therapies

Communication:

- Ensure that the family understand that the planned care is now focused on the care of the dying.
- Explain the process of withdrawing life-sustaining therapies.
- Offer support e.g. chaplaincy or preferred religious leader.
- Identify any religious or multi-cultural faith traditions that need to be respected.
- Allow sufficient time for family members/carers to spend with the patient prior to commencing withdrawal of supportive therapies.
- Confirm with medical staff if the patient is to be extubated or placed on T-piece. Offer family members to be present during the extubation procedure.
- Explain to family members that the bedside monitor display screen will be turned off.

Assessment of patient comfort prior to withdrawing supportive therapies:

- Discontinue any neuromuscular blocking agents e.g. atracurium or rocuronium.
- Assess the patient for pain using the CPOT and record the score on the patient's observation chart.
- Ensure that analgesic and sedative infusions have been commenced.
- Treat CPOT scores ≥ 3 with rescue bolus of analgesia.
- Discuss with medical staff appropriateness for anticipatory prescribing of midazolam infusion. This may be necessary for patient groups at risk of developing seizures e.g. cerebral injury/stroke.

Withdraw supportive therapies in the following sequence:

1. Stop all unnecessary iv infusions except for analgesic/sedative infusions and inotropic/vasopressor infusion.
2. Decrease oxygen therapy to room air i.e. 21%.
3. Maintain ventilator settings if patient appears uncomfortable and assess for pain. Titrate analgesia as needed to achieve patient comfort.
4. Whenever patient appears more settled, discontinue mechanical ventilation and proceed to either extubation or T-piece as agreed by medical staff.
5. Finally discontinue inotropic/vasopressor infusions.
6. Switch off the bedside monitor screen. Observe patient parameters via the central station monitor.
7. Maintain ongoing patient assessment using the care plan i.e. 'Anticipatory care of the dying patient undergoing treatment withdrawal'.
8. Ongoing communications between the family and medical staff are important.

Supporting healthcare colleagues:

- Inform team members of the plan to withdraw treatment as this will promote awareness and sensitivity of the situation.
- Support the bedside nurse that is caring for the dying patient and help share the workload in managing distressed relatives/carers.
- Offer nursing colleague(s) a break or respite following the patient's death.
- Assist nursing colleague(s) with grieving/feeling of loss by acknowledging their feelings and taking time to engage in debriefing sessions as appropriate.

Anticipatory Care of the Dying patient undergoing Withdrawal of Supportive therapies

No.	Actual/potential problem and assessment	Goal of care	Intervention	Outcome
1	The patient may show signs of pain such as grimacing, frowning, increased muscular tension/rigidity.	The patient appears to be pain free and comfortable.	1. Assess patient for pain using the CPOT. 2. Target pain score 0 to 1. 3. Treat CPOT score ≥ 3 with rescue bolus analgesia and assess effectiveness of same. 4. Refer to guidance for palliative care continuous intravenous opioid or subcutaneous opioid infusion and titrate pain to patient comfort.	If patient demonstrates signs of pain, record the appropriate action taken (outcome) in the nursing report/medical records.
2	The patient may show signs of agitation or distress.	The patient appears to be calm and undistressed.	1. Treat behavioural signs of agitation or distress with analgesia first, then sedate as required. 2. Assess patient for agitation using the Richmond Agitation Sedation Scale (RASS). 3. Target RASS score 0 to -5 4. Refer to guidance for palliative care continuous iv infusions and administer propofol/midazolam infusion(s)and rescue boluses as prescribed. Assess effect of same.	If patient demonstrates signs of agitation or distress, record the appropriate action taken (outcome) in the nursing report/medical records.
3	The patient may show signs of respiratory distress such as increasing breathlessness, gasping respiration, noisy airway or increasing respiratory secretions.	The patient's breathing appears comfortable and respiratory secretions are minimal.	1. Observe the patient for signs of respiratory distress. Assess the need to suction oropharynx or the tracheal tube as required. 2. Ensure patient is nursed in comfortable upright position. Consider change of position or positioning patient in lateral position to help alleviate noisy airway. 3. Administer bolus opioid as prescribed for respiratory distress. 4. Administer antimuscarinic drugs e.g. hyoscine butylbromide or glycopyrronium as per Highland Formulary guidance for increasing respiratory secretions.	If patient demonstrates signs of respiratory distress, record the appropriate action taken (outcome) in the nursing report/medical records.

Anticipatory Care of the Dying patient undergoing Withdrawal of Supportive therapies

NHS Highland

No.	Actual/potential problem and assessment	Goal of care	Intervention	Outcome
4	The patient may develop seizure activity as demonstrated by increased jerking, twitching, body stiffening or shaking.	Seizure activity is identified and treated so that seizures are controlled.	1. Observe the patient for signs of seizure activity. 2. Anticipatory drug prescribing e.g. midazolam for susceptible patient groups i.e. cerebral injury/stroke. 3. Inform family members regarding potential for seizure activity and the appropriate treatment that will be implemented. 4. Administer midazolam as prescribed and assess effect of same.	If the patient demonstrates signs of seizure activity, record the appropriate action (outcome) in the nursing report/medical records.
5	The patient may develop regurgitation or vomiting. This may be due to reduced level of consciousness gastrointestinal obstruction or dysphagia which may increase the risk of aspiration.	Vomiting is treated so that symptoms are relieved.	1. Ensure patient is nursed in comfortable upright position/lateral position with head-up to reduce gastric regurgitation. 2. If gastric regurgitation is problematic, consider retaining NG tube in situ to enable gastric decompression. 3. Administer anti-emetic as prescribed and assess effect.	If the patient demonstrates signs of vomiting, record the appropriate action (outcome) in the nursing report/medical records.
6	The patient may not be able to tolerate oral fluids/parenteral fluids due to impaired swallow reflex or unwanted effects of increasing respiratory secretions and oedema. Oral mucosa and tongue may become dry and patient may experience thirst.	The patient is kept adequately hydrated and does not demonstrate signs of thirst i.e. oral mucosa and tongue appears clean and moist.	1. IV fluids are usually discontinued as per medical staff's instructions. 2. Oral mucosa and tongue is assessed every hour. 3. Oral hygiene/moisturisation of lips is undertaken based on assessment. 4. Nursing staff will support the patient in receiving oral sips/ice cubes if the patient is able to tolerate.	If the patient demonstrates signs of dry oral mucosa or non-verbally communicates thirst, record the appropriate action (outcome) in the nursing report/medical records.

7	The patient's skin integrity needs to be assessed and pressure areas need to be relieved.	Prevent pressure ulcers developing and/or reduce further deterioration if a pressure ulcer is already present.	1. Assess the patient's pressure areas and maintain regular change of position to alleviate patient discomfort. 2. Ensure patient is nursed in comfortable position and ensure careful alignment of head, neck, shoulders and limbs. 3. Maintain pressure-relieving mattress.	If pressure areas are noted to be problematic, record action taken (outcome) in nursing report/ medical records.
8	The patient's personal hygiene needs are addressed.	The patient's personal hygiene needs are met and dignity and privacy is maintained.	1. Nursing staff will attend to personal hygiene needs such as bedbath, hair and nail care, oral hygiene, catheter care, bowel care. 2. Offer family members/carers to participate in attending to the patient's care as appropriate e.g. attention to eye/mouth care. 3. Respect the need for privacy and dignity at all times e.g. well-fitting curtains/screens or cubicle where possible.	Document any associated problems with personal hygiene needs in the nursing report/medical records.
9	The patient may have specific spiritual and/or multi-cultural needs.	The patient's spiritual and/or multicultural needs are met.	1. Chaplaincy support and/or attention to spiritual, religious, or cultural needs are facilitated as appropriate. 2. Consider that specific rituals may be needed e.g. sacrament of the sick.	It is appropriate to document when appropriate rituals have been addressed.
10	The patient's family members/carers may experience feelings of anxiety, distress and helplessness.	To ensure that family members or carers are continuously supported and comforted.	1. Ensure that medical staff have discussed all relevant issues with the family/carers and that the communications from the family meeting is documented in the clinical record. 2. Maintain a quiet environment. The bedside area offers adequate privacy and is clean and tidy. Ambient lighting is comfortable. 3. Allow and encourage the presence of family/close friends at the beside and are supported by music, prayer, silence, as preferred. 4. If the family member(s) require to leave the bedside: provide reassurance that they will be contacted if the patient's condition suddenly changes. 5. Offer quiet facilities for contemplation e.g. visitors room/chapel.	Document that family have received appropriate comfort and support.

Care After The Patient Has Died

Immediate care of the family after the patient has died:

- The family member(s) or carer(s) are offered private time to be with the patient immediately after death.
- The opportunity for exercising cultural, religious or spiritual comfort is offered e.g. ritual, prayer or music.
- Support of the chaplaincy or religious leader is offered.
- The family member(s) or carer(s) are offered the opportunity to participate in attending to the last offices.
- Discuss as appropriate: viewing the body at a later time after death/the need for a post-mortem or discussion with the Procurator Fiscal.

Care of the patient after death:

- Obtain hand prints or lock of hair from the patient as appropriate.
- Last offices are undertaken. The privacy and dignity of the patient is maintained.
- The patient is dressed in suitable clothing or clothing according to the wishes of the family.
- Confirm with the family – any jewellery that is to remain on the patient or any personal mementos that are to remain with the patient.
- Universal precautions and hospital policy and procedures are followed including infection control measures.
- Ensure all relevant details are completed on the mortuary admissions document.

Relevant information exchanged with the family member/carer:

- 'When someone has died booklet' is issued.
- Death certificate: local policy is for ICU nursing staff to contact the Bereavement Officer, who will then hand over a death certificate for medical staff to complete.
- Issuing death certificate: the death certificate may not always be issued immediately. Local policy is that the Bereavement Officer will contact either the relatives or the funeral undertaker and arrange for them to uplift the completed death certificate as soon as it is ready for collection.
- Registering the death: once the death certificate is issued the family will need to telephone and book an appointment with the Registrar.
- A signature is obtained from the family member/carer to confirm that the patient's belongings and valuables have been returned to them.

ICU administration:

The patient's death is -

- Entered on the patient management system.
- Recorded in the ICU admissions book.
- Entered on the Ward Watcher system.
- Communicated to the patient's GP.