Guidance for Withdrawal of Non-Invasive Respiratory Support

TARGET AUDIENCE	Secondary care physicians
PATIENT GROUP	Adult patients on NIV / CPAP / HFO_2

Clinical Guidelines Summary

The flow chart on the following page illustrates the process that staff involved in caring for patients on Non-Invasive Ventilation (NIV), Continuous Positive Airways Pressure (CPAP) or High Flow Oxygen (HFO_2) should follow where the decision has been made to move to symptomatic care and respiratory support is being discontinued

Key to colour codes

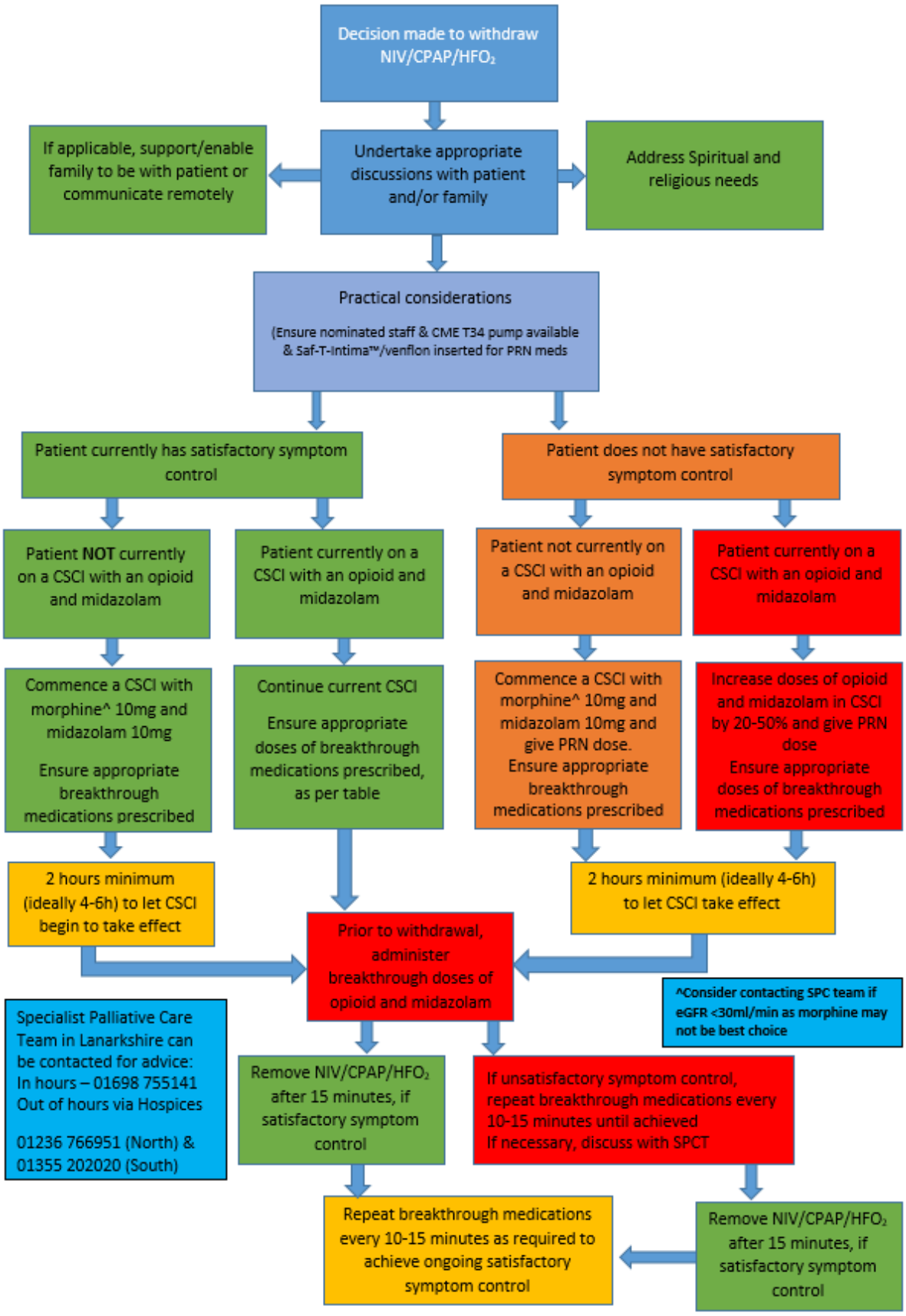
Blue- information

Green- easy/straightforward

Amber- something to look out for

Red- significant action required

Guidance for Withdrawal of Non-invasive Respiratory Support



Lead Author	**Sandra McConnell**	**Date approved**	**15.05.2024 (ADTC)**
Version	**1.0**	**Review Date**	**May 2027**

Contents

1. Purpose of the Document
2. Circumstances for Withdrawal
3. Practicalities
4. The Process of Withdrawing NIV, CPAP or HFO2
5. Medication
6. Additional Resources/References

1. Purpose of the Document

The purpose of this guideline is to provide information for staff involved in caring for patients on Non-Invasive Ventilation (NIV), Continuous Positive Airways Pressure (CPAP) or High Flow Oxygen (HFO_2) where the decision has been made to move to symptomatic care and respiratory support is being discontinued.

2. Circumstances for Withdrawal

- The patient requests to discontinue their NIV / CPAP / HFO2
- The patient is not tolerating NIV / CPAP / HFO2
- The patient is not recovering from their illness
- The patient continues to deteriorate despite NIV / CPAP / HFO2
- The patient has been placed on NIV / CPAP / HFO2 as a bridge to decision making regarding escalation of care and consequently the therapy needs to now be discontinued.

Explanations to patient/family in the case of a medical decision to withdraw:

- The patient has '*x*' (offer full explanation of background diagnosis).
- Despite maximal appropriate therapy, the patient continues to deteriorate and there are no signs of recovery. We now do not expect the patient to survive this illness and it is no longer appropriate to artificially prolong life with such treatment which may prolong the dying process.
- The current treatments should/will be removed as they are not effective.
- The plan of care will now be to focus on those interventions that prioritise the comfort of the patient.
- Our primary aim now is to alleviate any symptoms such as pain, distress or breathlessness.
- The patient is expected to rapidly deteriorate and die.
- If the patient or family disagree with the clinical decision to withdraw NIV, this will require careful communication and may require consideration of a second opinion

Thereafter, you should offer to discuss the patient's and family's wishes and expectations regarding the practicalities of withdrawal:

- Spiritual care should be explored and offered.
- Stopping NIV / CPAP / HFO2 may lead to distressing breathlessness.
    - Any distress can be managed with medication via continuous subcutaneous infusion (CSCI) and top up injections. These medicines can cause sleepiness. Sometimes people prefer to be awake with good symptom control if possible, whilst others prefer to be more sedated so that they are unaware of the situation. Ask patient about their preference.
- Switching to O2 via venturi mask can prolong the dying process and potentially increase distress for all involved. If the idea of having no oxygen causes distress for family, you could consider a small flow of supplemental oxygen therapy via nasal prongs.
- Enquire if the patient wishes family to be present at time of mask withdrawal (and whether family wish to be present). If family are going to be present, offer to explain the changes they will see e.g. cyanosis, altered breathing pattern etc.
- Warn family that although patients often deteriorate and die within minutes to hours, occasionally this can take longer.

3. Practicalities

- Discussion with patients, families and carers is best practice however we must be accepting that in an emergency, decisions should not be delayed.
- If applicable, initiate plans to allow relatives to attend the hospital to visit prior to withdrawal (if not already present and/or fully updated).
- If the relatives are unable, or choose not to attend, they should be offered the opportunity, where possible, to communicate with their relative before withdrawal – this could be by audio or video technology.
- DNACPR should be in place.

4. The Process of Withdrawing NIV, CPAP or HFO2

- The clinicians involved in the withdrawal will need to think through the practicalities of potentially giving repeated doses of medication while remaining present and maintaining any relevant infection control measures (i.e. not coming in and out a room for example).
- The clinician involved should familiarise themselves with the ventilator before withdrawal takes place: as a minimum they must know how to turn off the machine and turn off or adjust alarm settings.

- It is not common practice to "wean" patients from NIV / CPAP / HFO_2 by reducing ventilator settings or O_2 percentage as this can prolong dying and increase the discomfort experienced by the patient. It should be stopped and removed in one go. NB Guidance for withdrawal in patients with NIV for MND is different – see p20 in APM guidance on link below in resources
- Symptoms should ideally be controlled prior to the removal of the therapy and it should be anticipated that the patient may experience breathlessness and distress.
- The patient should ideally be commenced on a continuous subcutaneous infusion (CSCI) of an opioid and midazolam, at least 2 hours (preferably 4-6hours) prior to commencing withdrawal. Patient will usually then need at least one 'as required' dose, in addition to the CSCI, prior to the mask being removed.
- A BD Saf-T-Intima™ cannula should be inserted to aid the administration of subcutaneous (SC) medications, if a venflon is not in situ for intravenous (IV) doses of ' as required' medications (see below).
- The focus of care during withdrawal is symptom control and the patient may require multiple doses of medication to control their symptoms both prior to and after the withdrawal of treatment.
- **If the patient's symptoms are not controlled with the above steps, please seek advice from the Specialist Palliative Care Team prior to commencing withdrawal.**

5. Medication

Symptoms of breathlessness and distress can be anticipated and can be effectively managed.

Assess the patient **prior** to withdrawal:
1. Is the person's work of breathing high / respiration rate high?
2. Are they in pain?
3. Are they are already distressed or agitated?
4. Are there audible respiratory tract secretions?
*5. Does the person have functioning IV access? - this route has a quicker onset of action**

The choice of drugs will depend on what the patient is already on:

- If they are already on a CSCI with an opioid and midazolam and **these are effective,** give a dose of their usual breakthrough opioid (usually $1/6^{th}$-$1/10^{th}$ of total 24hr dose) and a dose of subcutaneous or IV midazolam (see table below).
- If the patient is already on a CSCI with an opioid and midazolam and **these are not effective,** increase the dose by 20- 50%, depending on the severity of symptoms, and alter the dose of breakthrough medications accordingly (usually $1/6^{th}$-$1/10^{th}$ of total 24hr dose).

Guidance for Withdrawal of Non-invasive Respiratory Support

- If the patient is **already on an opioid or benzodiazepines** regularly/long term but **not via a CSCI**, please consult the Scottish Palliative Care Guidelines https://rightdecisions.scot.nhs.uk/scottish-palliative-care-guidelines/ for guidance as to how to convert to a CSCI or contact the Specialist Palliative Care service for advice.
- In patients who are **naive of symptom control medication** consider commencing a CSCI with morphine** 10mg and midazolam 10mg and the following anticipatory medications (see table below):

Symptom	Drug	SC dose	IV (as alternative to SC)
Breathlessness or Pain	Morphine**	2mg - 5mg	2mg - 5mg
Distress/anxiety	Midazolam	2mg - 5mg	2mg - 5mg
Secretions	Hyoscine Butylbromide	20mg	
Agitation	Levomepromazine	2.5mg - 5mg	

** IV route should take around 3 - 5 minutes to be effective while subcutaneous is around 10-15 minutes. Repeated doses can be utilised as necessary to achieve comfort, taking these times into account.*
*** Alternative opioid may be indicated if renal impairment – see Scottish Palliative Care Guidelines* https://rightdecisions.scot.nhs.uk/scottish-palliative-care-guidelines/end-of-life-care/renal-disease-in-the-last-days-of-life/

It is expected that all patients will be distressed, commonly with dyspnoea and/or agitation. They will therefore need a dose of opioid and midazolam **prior** to withdrawal (in addition to their CSCI).
If the patient is not comfortable prior to withdrawal, please seek advice from the Specialist Palliative Care Team.

Remove the NIV / CPAP / HFO_2 once the patient has been made as comfortable as possible.
In the time frame after withdrawal, there may be a need to repeat doses of these medications.

- If IV access is present, breakthrough medications can be given IV rather than SC.
- A Saf-T-Intima™ cannula should be inserted to allow repeated SC injections in the absence of IV access.
- Some patients cannot be awake without being distressed and may require repeated doses of midazolam, in addition to a syringe pump, to make them comfortable.

When respiratory support is removed, patients will often deteriorate and die over minutes to hours, although occasionally this may take longer.

The purpose of these medications is not to shorten life but to appropriately reduce the patient's awareness and distress as they approach the end of life.

6. Other Resources

A wealth of guidance can be found in the **Scottish Palliative Care Guidelines** at https://rightdecisions.scot.nhs.uk/scottish-palliative-care-guidelines/

Anticipatory care planning (REDMAP) on Turas Learn: https://learn.nes.nhs.scot/60446

Additional information about withdrawal of NIV in people with Motor Neurone Disease:

Microsoft Word - Guidance with logos updated 210316.docx (apmonline.org)

Mechanical ventilation withdrawal in motor neuron disease: an evaluation of practice | BMJ Supportive & Palliative Care

Specialist Palliative Care Team in Lanarkshire can be contacted for advice:

In hours – 01698 755141

Out of hours via Hospices –

01236 766951 for St Andrew's Hospice in the North

01355 202020 for Kilbryde Hospice in the South

Appendices

1. Governance information for Guidance document

Lead Author(s):	Dr Sandra McConnell, Consultant in Palliative Medicine, NHSL Dr Nicholas Holt, Consultant in Acute and General Medicine, NHSL
Endorsing Body:	Area Drugs and Therapeutics Committee, NHSL
Version Number:	1.0
Approval date	May 2024
Review Date:	May 2027
Responsible Person (if different from lead author)	Linda Johnstone, Macmillan Area Lead Pharmacist-Palliative Care, NHSL

CONSULTATION AND DISTRIBUTION RECORD	
Contributing Author / Authors	Claire Marshall
Consultation Process / Stakeholders:	NHSL Specialist Palliative Care Drugs & Therapeutics Group NHSL Deteriorating Patient Group (UHM) NHSL Acute Consultants Group (UHM) NHSL Medical HDU Group (UHM) Several Consultant Physicians in UHH and UHW Chief Nurse at UHH and UHW
Distribution	All Palliative Medicine Consultants All Acute and General Medicine Consultants

CHANGE RECORD			
Date	**Lead Author**	**Change**	**Version**
		e.g. Review, revise and update of policy in line with contemporary professional structures and practice	1
			2
			3
		.	4
			5