Guideline for the withdrawal of non-invasive types of respiratory support in the hospital setting

University Hospitals of Leicester NHS
NHS Trust

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1. INTRODUCTION

Non-invasive forms of respiratory support (NIRS):

The use of non-invasive assisted ventilation (NIV) and other types of support (HFNO) has increased in recent years for patients with a variety of diagnoses. Depending on the setting, NIV can provide benefit both to prognosis and to symptom control. The symptomatic benefit can occasionally extend to patients who have been recognised to be in the last days of life.

Types of non-invasive forms of respiratory support (NIRS):

A. **CPAP (Continuous positive pressure airway pressure)**

- Provides the same amount of pressure during inspiration and expiration.
- Often used in obstructive sleep apnoea or in some patients with pulmonary oedema.

B. **BiPAP (Bilevel positive pressure airway pressure)**

- Provides a different level of pressure during inspiration and expiration.
- Often used in the acute setting for patients with COVID pneumonitis but also for patients with diagnoses like COPD and MND both in the acute setting or as a long-term treatment.

C. **HFNO (high flow nasal oxygen):**

- The delivery of heated, humidified oxygen via a nasal cannula, at inspiratory flows higher than those achieved with the standard oxygen devices.
- May be offered to patients with Type I RF.

These treatments can be used either as a long-term treatment in a community setting (e.g. patients with COPD) or as a short-term treatment in hospital when patients become critically unwell.

It is of note that some patients on long-term NIV may become more dependent on this whilst acutely unwell. This may present as a difficulty in discontinuing treatment even for short periods of time e.g. with COVID pneumonitis, acute exacerbation of COPD, acute admission with ILD.

2. SCOPE

This guideline aims to support the healthcare team through the process of a withdrawal of NIRS in the hospital setting for a patient who is deteriorating or who requests the withdrawal of their NIRS.

Some patients will deteriorate whilst receiving NIV or may start to find it a burdensome intervention. On those occasions, the medical team should review the role of NIV in the ongoing

management of the patient. The family and, where possible, the patient should be involved in this review.

Any patient with capacity to make decisions about life prolonging or life sustaining treatment may make a request at any time to withdraw NIRS, even if doing so will likely shorten their life.

If a patient who is stable on their NIRS is requesting withdrawal of their NIRS even when not acutely unwell, involvement of the respiratory team or palliative care team for additional assessment and support may be useful.

3. RECOMMENDATIONS, STANDARDS AND PROCEDURAL STATEMENTS

Procedure / Process for NIRS/NIV withdrawal	
No.	**Action**
Step 1	Consideration of the NIV withdrawal - assessing the situation
Step 2	Communicating and documenting the decisions
Step 3	Planning the withdrawal
Step 4	Prescribing
Step 5	Withdrawal of NIRS
Step 6	Care of patient and family after withdrawal
Step 7	Team debrief and self-care

Step 1: Consideration of NIV withdrawal and assessing the situation

Key facts:

- Non-invasive ventilation (NIV), or non-invasive respiratory support (NIRS) is a medical treatment.
- Withdrawal of NIV is not euthanasia or assisted dying. It is the stopping of a medical treatment that is either harmful or no longer adding clinical benefit.
- Any patient with the mental capacity to make decisions about life-prolonging or life-sustaining treatments has the right to request withdrawal of a medical treatment, even if they were to die as a consequence of the withdrawal.
- NIRS can be continued at the end of life if it provides symptomatic benefit. There is no need to withdraw treatment if the patient is identified as dying but is comfortable and tolerated their NIRS.

Withdrawal may be considered in the following situations:

1. Patient is deteriorating despite NIRS and NIRS is not offering any additional benefit, such as symptom control.
2. Patient not tolerating treatment or distressed as a result of the use of NIV, despite the use of pharmacological measures to control symptoms
    a. Restlessness, pulling off the mask, and turning of the head can all be signs of agitation due to the NIV.
    b. Exclude other causes of distress e.g. uncontrolled physical symptoms, urinary retention, constipation.
3. Patient with capacity asking for withdrawal of NIRS after a full discussion with a senior member of the team (StR level and above) regarding the risks and consequences.
4. Patient without capacity who has a valid Advance Decision to Refuse Treatment (ADRT) and his/her condition deteriorates so that the ADRT becomes applicable.

Decision making:

- A senior clinician (StR or consultant) must be involved in the process of decision making.
- Senior nurses, nurses familiar with the patient, NIV/respiratory support team members (DART), physiotherapy and other team members involved in the patient's care, as well as palliative care senior doctors and specialist nurses can all offer support with decision making.
- Check if there are any previously documented advance care plans or preferences relating to NIRS removal – for example on a ReSPECT plan or in an ADRT (advance decision to refuse treatment) document.

Patients lacking mental capacity who are being considered for withdrawal of NIRS:

- Ensure MCA assessment (specifically relating to withdrawal of NIRS) is clearly documented in the medical notes.
- Check if there is a valid Lasting Power of Attorney for Health and Welfare in place. If so the LPA must be consulted.
- If no LPA, the next of kin and other persons identified as important to the patient must be consulted, and decisions must be made in the best interests of the patient (taking into consideration previously expressed wishes of the patient).
- Check if the patient has a valid and applicable ADRT. If so, the ADRT must be followed.
- For patients with capacity, an awareness of previously documented wishes can help to keep the conversation more focused on the priorities of care, especially as the fatigue and the use of the respiratory support can make communication more difficult. Patients with capacity should be fully involved in the decision-making and planning of a NIRS withdrawal.

Patients with mental capacity, who are being considered for withdrawal of NIRS:

- Discuss the withdrawal sensitively, preferably in the presence of family or those identified as important to the patient.

Timing of withdrawal:

- Most withdrawals can be done in a non-urgent way.
- Consider an urgent withdrawal if the patient is severely agitated and this is felt to be related to the NIRS.

Step 2: Communicating and documenting the decisions:

The priority during withdrawal of NIRS is the patient's comfort, the management of distressing symptoms, and offering support to the patient, family, and the staff involved.

- Discuss and update the persons identified as important to the patient (family/NOK) of discussions and decisions around withdrawal, ideally with them present and a face-face discussion.
- Document the discussions in the patient notes.
- Update the paper ReSPECT form to reflect the decision of withdrawal to avoid re-introduction at a later stage, unless there is a specific plan to do so.
- Decisions around resuscitation and escalation plans should also be updated on Nervecentre to allow easier communication between the teams.
- On occasions when a patient wishes to try and remain alert during the withdrawal, consider discussing this with the specialist palliative care team to share the planning, including about what to do if the patient becomes very symptomatic.

- This could include the temporary re-introduction of the NIRS whilst adjusting the doses of the medication to alleviate the distress, if the patient consents to this (for a patient with capacity). This needs to be considered, discussed and agreed prior to the withdrawal.
- Ensure that the whole team is aware of the withdrawal so that assistance can be easily sought if needed.
- If not already involved, the Palliative Care Team can be contacted for further support.
- Consider whether the patient has any religious needs i.e. offer Chaplaincy input and explore whether early release of the body may be needed.

Step 3: Planning the withdrawal:

Careful planning and preparation prior to going to the patient's bedside will increase the likelihood of a smooth withdrawal.

Essential roles checklist:

- Prescriber (e.g. Doctor, ACP, Clinical Nurse Specialist)
- 2 persons authorised to check controlled drugs (e.g. Nurse)
- Person to administer medicines
- Person who is familiar with the NIV device and will be in charge of removing it (e.g. Physiotherapist, Ventilation Nurse, ward Nurse)
- Scribe, to keep a record of time, medications and doses used etc

Other roles to consider:

- Relatives or friends - discuss whether anyone would like to be present during the withdrawal, sensitively exploring what will be involved.
    - Decide as a team who will support the family throughout the withdrawal.
    - Video calls can be offered as an alternative to their face to face presence.
- Palliative Care Team - may already be involved, can support with advice on optimising symptom management before and during the withdrawal.
- Chaplaincy - enquire about any religious or spiritual needs.

Practical steps before the withdrawal:

- See whether your bleep/work phone can be given to someone else - withdrawal of NIRS can take some time, and the aim is to have a calm and undisturbed environment.
- Clarify which PPE needs to be worn, and whether family also need to wear this.
- Insert 2 separate subcutaneous lines - for administration of symptom control medicines before and during the withdrawal.
- Draw up two doses of Morphine (or Oxycodone) and two doses of Midazolam (see doses below) before withdrawal.

Plan for oxygen:

- Plan whether O2 will be delivered after removal of NIRS.
- Which oxygen device will be used?
- If able, involve the patient in this process.
- Depending on patient's preference and previous symptom burden, this could be:
    - no oxygen
    - oxygen via non-rebreathe mask

    - HFNO
- Discuss the possibility of NIRS potentially being temporarily re-applied during the withdrawal process i.e. if the patient becomes very symptomatic whilst waiting for medications to take effect.

Timeframes:

- The duration of time between withdrawal of NIRS and death varies between each individual.
- Patients who are fully dependent on NIRS often deteriorate and die rapidly once this is discontinued i.e. within minutes-hours.
    - This needs to be communicated clearly to the family.
    - Patients may exhibit dependency through being unable to tolerate short treatment breaks (seconds to minutes), without severe exacerbation of symptoms.
- Some patients can live several hours once NIRS has been withdrawn - it is important that the clinical team involved and the patient's family/friends are aware of this.

Remain observant and considerate of the emotions and the reactions of the team around you, as well as your own emotional response throughout the process. Do not hesitate to ask for support at this stage, if the team are worried about the withdrawal. A structured support and debrief after the acute phase can be helpful to maintain the team's resilience and well-being (see more at the end of the guidance).

Step 4: Prescribing:

The aim is to maintain comfort throughout the process. Once removal is agreed, this often involves the use of medication to make the patient less aware of any distressing symptoms.

Important notes:

- Repeated doses of PRN medication may be needed at doses higher than the standard doses used in the last days of life.
    - The standard, starting doses of medications are indicated below but those could vary depending on the patient's previous exposure and use of opioids and level of symptom distress.
- If in any doubt, please discuss with the palliative care team prior to the withdrawal.
- Patients who appear to be dependent on their respiratory support and are unable to tolerate even short breaks of treatment without worsening of their symptoms are more likely to become distressed and symptomatic at the time of the withdrawal.

Suggested PRN medicines for symptom control - ensure these are prescribed prior to withdrawal of NIRS:

❑ **Morphine sulphate 5-20mg** - subcutaneous PRN, minimum interval 15 minutes, for pain/breathlessness (when eGFR >50)

❑ (or) **Oxycodone 2.5-10mg** - subcutaneous PRN, minimum interval 15 minutes, for pain/breathlessness (when eGFR <50, or previous side effects with Morphine)

❑ **Midazolam 5-20mg** - subcutaneous PRN, minimum interval 15 minutes, for

anxiety/distress/agitation

❑ **Levomepromazine 12.5-25mg** - subcutaneous PRN, minimum interval 15 minutes, up to 200mg/24hrs, for anxiety/distress/agitation

❑ **Glycopyrronium 200-400micrograms** - subcutaneous PRN, minimum interval 30 minutes, up to 1.2mg/24hrs - for symptomatic respiratory secretions

Other factors to consider:

- Patients who are already on regular opioids or benzodiazepines may need higher doses.
    - For patients already established on opioids/benzodiazepines, discuss the starting doses of medication with the palliative care team.
- The IV route can be used instead of the SC if a secure IV access is available or rapid titration of medication is needed.
- When a withdrawal is done in a non-emergency situation, consider starting a continuous subcutaneous infusion (CSCI) at least 4 hours prior to the withdrawal to promote comfort.
    - Doses will depend on the intensity of symptoms, previous use of medication and patient's characteristics and co-morbidities. Discuss with the palliative care team.

Step 5: Withdrawal:

The aim is to provide comfort and control of symptoms throughout the withdrawal of NIRS.

Some people may become sleepy but others may still be awake.

The aim of the symptomatic treatment should be discussed and agreed prior to the withdrawal.

1. Offer medication just prior to the withdrawal	❑ Assess the patient's comfort prior to removal of the NIRS ❑ Non-verbal signs of distress - facial expressions, tension of the body, the level of agitation, as well as verbal cues can help with the assessment. ❑ The level of required sedation can vary depending on the patient's aims and wishes. ❑ Administer doses of Morphine (or Oxycodone) and Midazolam (even if the patient currently appears comfortable - it is anticipated that they will become symptomatic once NIRS is removed) ❑ Start with the lower doses, and titrate as needed ❑ The medication should work within 10-15 minutes ❑ Offer repeated doses in 15-minutes intervals until the patient appears comfortable and not distressed ❑ Note that if the previous doses offered some, but not full effect, the doses of both the Morphine and the Midazolam can be increased further in 5 mg steps (or 2.5mg steps for Oxycodone). ❑ If Midazolam at doses above 10 mg fails to provide significant

	benefit in controlling severe agitation or signs of fear and distress, Levomepromazine can be used in addition to Midazolam. If the symptoms aren't controlled contact the hospital palliative care team urgently during normal working hours (LRI number: 0116 255414, 07950888434, GH number: 0116 258 3540, 07866185929) or the on-call consultant for palliative care via switchboard, if out of hours.
2. Removal of NIRS and change of the method of oxygen delivery	❑ It is essential that a member of staff who is familiar and confident in using the NIV/CPAP machine is in charge of this step ❑ Ensure that monitoring and alarms are turned off on the machine ❑ If the patient is comfortable, switch off NIV/CPAP ❑ Alternatively, the pressures can be weaned in a stepwise manner ❑ Replace the mask directly with the chosen method of Oxygen delivery. This depends on your previous discussions with the patient. ❑ Stay with the patient throughout this process and continue to monitor closely for at least 15 minutes following the withdrawal.
3. Re-assess for symptoms	❑ Repeated doses of medication may be needed for symptom control. ❑ If severe distress occurs NIRS may need to be re-introduced temporarily until distress is managed pharmacologically, if the person has accepted this during the discussions about the process.

Specific groups of patients

(1) People with infections that may be more transmissible when high level respiratory support is being used:

- The removal of assisted ventilation can reduce the risk of infection to visitors which can be very important for some patients.
- If family are present during the withdrawal consider and encourage their protection via the use of protective equipment.

(2) People with MND or other neuromuscular conditions:

- These patients may be well established on their NIV. They may find it comforting/necessary for symptom control and/or be familiar and comfortable with it use, even if it is offering less clear clinical benefit. On those occasions, continuing with the NIV until the time of death may be appropriate.

- If a withdrawal is planned, the patients who are completely dependent on NIV may become very symptomatic once the treatment is withdrawn. The process of the withdrawal

is similar to above but the starting doses of medications are higher (suggested doses Morphine 10-15 mg and Midazolam 10-15 mg SC stat).

- For patients who are using their NIV intermittently the aim should be to not re-start the treatment once is this is off and to manage the symptoms pharmacologically (suggested doses Morphine 5-10 mg SC, every 15 mins. Midazolam 5-10 mg SC can also be offered alongside Morphine to alleviate distress).

(3) COPD patients:

- As with MND patients, COPD patients may be very familiar with their NIV and may find its use comforting. As above, the patients who are more dependent are more likely to become symptomatic.

- If the patient is dependent on NIV an alternative process would include weaning down the pressures in a gradual way in 5 minutes intervals. Medications are offered just prior to the first reduction of the pressures. In response to symptoms, further doses can be offered every 15 minutes, as per the standard withdrawal guidance.

Step 6: Planning for the patient's care after the withdrawal:

- Support the family during their visit, if present, by ensuring they are fully informed of steps taken and encouraged to be close to their loved one. If not, ring them and inform them immediately after you leave the patient's room.

- If the patient appears settled and hasn't died immediately following the withdrawal, consider the use of a continuous subcutaneous infusion (CSCI) to maintain comfort if one is not already in place.

- Doses of the medication in the continuous subcutaneous infusion (CSCI) will need to be proportionate to what was needed during the withdrawal. The palliative care team can give further advice on this. Ensure that you know all the medication used and at what doses to facilitate appropriate calculations of the doses.

- Ensure that the equipment (CPAP/NIV) is removed from the patient's room.

- Document in the patients notes the time of the withdrawal and the medication used.

Step 7: Team debrief and self-care

- Withdrawal of NIRS can be a highly emotive experience for all involved - allow yourself some time to process the events.

- Check in with your colleagues and support each other.

- Arrange a formal debrief session to protect the team's wellbeing.

- If concerns among the team or for individuals persist, remember to talk with the people around you: nurse in charge of the ward, senior doctors/clinical and education supervisors, AMICA.

4. EDUCATION AND TRAINING

Support and information on prescribing palliative care medication and continuous subcutaneous infusions (CSCI) can be found on HELM under module 'Meds Nervecentre Prescribing'.

5. MONITORING AND AUDIT CRITERIA

All guidelines should include key performance indicators or audit criteria for auditing compliance.

Key Performance Indicator	Method of Assessment	Frequency	Lead
Compliance with Guidelines	Audit – sample of cases	Yearly	Dr James Coxon

6. SUPPORTING DOCUMENTS AND KEY RESOURCES

Glossary:

NIRS - Non-invasive forms of respiratory support

NIV - Non-invasive ventilation

CPAP - Continuous positive airway pressure

BiPAP - Bilevel positive airway pressure

HFNO - High-flow nasal oxygen

NRB - Non-rebreathable mask

ADRT - Advance decision to refuse treatment

ACP - Advance care planning

ReSPECT - Recommended Summary Plan for Emergency care and treatment

CSCI - Continuous subcutaneous infusion-administered via a T34 pump in UHL.

References:

Withdrawal of assisted ventilation at the request of a patient with Motor Neuron Disease, APM, 2015

Support documents:

NIV withdrawal visual guide

7. EQUALITY IMPACT ASSESSMENT

The Trust recognises the diversity of the local community it serves. Our aim therefore is to provide a safe environment free from discrimination and treat all individuals fairly with dignity and appropriately according to their needs.

As part of its development, this policy and its impact on equality have been reviewed and no detriment was identified.

8. KEY WORDS

NIV/NIRS withdrawal, non-invasive ventilation/CPAP, withdrawal

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This table is used to track the development and approval and dissemination of the document and any changes made on revised / reviewed versions

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Appendix 1 – Visual Guide to NIRS Withdrawal