Guidelines for withdrawing Non-Invasive Ventilation (NIV) at End of Life.

Background

What Is NIV and what is it used for?
Non-invasive ventilation (NIV) is a method of supporting the breathing. It is administered by a cushioned mask and does not involve an artificial airway. The air is pressurised at different pressures through the breathing cycle to help the patient to take breaths and keep the airway open. Most patients will only use NIV for parts of the day or night. However, some are dependent on NIV 24 hours of the day. For these patients, withdrawal of their NIV may cause distressing symptoms and death may occur soon after withdrawal. For these reasons forward planning is required.

NB. This guideline may also be applicable to those patients who are ventilated via a tracheostomy outside of an intensive care setting

Why do we withdraw NIV and who decides?
NIV can be used to treat patients with compromised respiratory function due to a number of different medical conditions. Many of these conditions are progressive and life-limiting. Patients may reach a stage when the burdens of continuing NIV outweigh the benefits they get from it. This may prompt a decision to withdraw NIV. A competent patient is entitled to make a decision to stop NIV treatment. Also if a non-competent patient has a valid advanced care plan or a decision to refuse treatment relating to NIV this should be respected. If there is doubt as to whether a patient has capacity to make decisions about withdrawal of life-sustaining treatment, this should be carefully assessed by the healthcare team involved in their care. In some situations where the patient lacks capacity to make a decision, the decision to withdraw NIV may be a best interest decision under the Mental Capacity Act, initiated by the medical team caring for a patient who has reached the last days of life when the NIV is no longer in the patient’s best interest.

It is helpful to initiate discussions about withdrawal of NIV at an earlier stage rather than leaving it to the last days of life. These conversations can be initiated if it is anticipated that the patient may need NIV or if NIV treatment is planned or in place.

Ethical issues
Decisions about stopping treatment at the end of life are emotionally distressing and some may involve ethical dilemmas. Some members of the healthcare team or the patient’s friends or family may find it difficult to contemplate withdrawal of a life-sustaining treatment. A common concern is that this may be tantamount to assisted suicide. However, the withdrawal of a medical treatment is not equivalent to actively hastening a patient’s death. The withdrawal of the treatment, whether at the request of a competent patient or following a consideration of best interests in a patient who lacks capacity, allows the underlying disease to take its natural course, which had been temporarily delayed by the NIV. These issues need to be explained to all involved prior to withdrawal. This can be a distressing time for those close to the patient and staff involved in their care. The need for bereavement support should be addressed at an early opportunity. Staff support mechanisms, including debriefing sessions, need to be considered.
How to go about it- withdrawal of NIV for patients who are 24 hour dependent

Patients who are not 24 hour dependent on NIV
These patients can discontinue NIV at any point by simply not replacing their mask. This may result in increased dyspnoea requiring appropriate symptom control. Appropriate medications should be prescribed for this purpose.

Who should be involved?
It is important to involve the right people to plan and support this process. For all patients a palliative care consultant and CNS and a CNS non-invasive ventilation should be involved at an early stage. The medical and nursing team caring for the patient are of key importance. At home this will be the GP and district nurses, in hospital or hospice it will be the consultant and ward staff. Some staff members may find this process difficult and consideration should be given to explaining the process and supporting staff before, during and after withdrawal of NIV.

Discussions with patient and family regarding withdrawal of NIV
Discussions ideally should include the Palliative Care CNS and the CNS non-invasive ventilation and should take place with the patient, family and carers and members of the MDT to ensure that all understand the reasons for withdrawing NIV, to plan how it will happen and explain what will happen to the patient as a result of withdrawal. This is a big decision to make and those involved should be given time to reflect and to discuss these issues several times if needed. The following points should be included in the discussion and an information leaflet should be given to the patient and family detailing the key points.

1) When does the patient wish to withdraw NIV? Consideration should be given to anything the patient wishes to attend to before withdrawal such as saying important things to friends and family and resolving their affairs. In general withdrawal should be planned to take place in normal working hours and when all necessary staff are available to support this.

2) Where will NIV be withdrawn? Options include in hospital, at home or in a hospice. Although professionals will be sensitive to the patient and family’s need for privacy, it should be explained that a number of professionals will be involved. This can be particularly difficult at home as all the professionals involved will be present in the home for this process.

3) Who will be present? This will include the professionals who need to be present to support the process. The patient and family should consider which family members or friends may wish to stay with the patient. A professional involved in the withdrawal will remove the mask. If the patient and family specifically ask for a family member do this it should be given careful consideration and discussion should occur with those involved. No family member should feel under pressure to undertake this responsibility.

4) How will the NIV be withdrawn? At home this will be by complete removal of the NIV after the comfort of the patient has been ensured. In general this is the preferred option in all settings. However, in hospital some patients may undergo a gradual reduction of the ventilation pressure called weaning.

5) How will we make sure the patient is comfortable? Medication is used to ensure the patient is not aware of the NIV being withdrawn and does not become uncomfortable or distressed. In general medications are given by injection before withdrawal is started. In addition a continuous infusion of medication may be used. These medications will make the patient more sleepy before withdrawal is started.
6) Will the NIV mask be replaced by an oxygen mask? This should be discussed and a decision made for each patient on an individual basis.

7) What will happen to the patient once the NIV is withdrawn? If a patient requires NIV 24 hours a day then it is likely that they will die soon after the NIV is withdrawn possibly within minutes. However in some cases it can take hours or even days. Inform the patient and family that physical changes will occur including that the patient may change colour and their breathing may change and become shallower and eventually stop.

**Planning the process of withdrawal.**
Once a decision has been made to withdraw NIV, planning for the process should begin. The following flowcharts show the processes that should be followed for complete withdrawal and weaned withdrawal. At this stage it is important to determine which professionals will be responsible for each task. In practice professionals may be responsible for more than one task. The following responsibilities should be allocated:

- Co-ordinating the planning and process of withdrawal of NIV
- Leading discussions with the patient and family
- Ensuring adequate medications are prescribed and available at the location
- Administering medications
- Turning off or reducing pressures of NIV
- Removing the NIV mask and if appropriate replacing with an \( \text{O}_2 \) mask
- Providing emotional support to family and friends
- Performing personal care after death (last offices)
- Completing death certificate and cremation form if required

**Medications**
It is important to ensure adequate medications are prescribed and available to control any symptoms during the process of withdrawal. All patients should be referred to the palliative care team. At a minimum the following medications should be available in injectible form:

- Diamorphine (or alternative strong opioid)
- Midazolam
- Haloperidol
- Hyoscine Butylbromide

In general patients should be given doses of medication before withdrawal occurs and may also require a continuous infusion of medication. Patients may need large doses to ensure they don’t become distressed. This should be carried out under the supervision of the palliative care team. If intravenous access is available this may be used. If it is not or if the patient is at home the subcutaneous route should be used.

NB: A patient who has already been on opioids, benzodiazepines or other sedatives may need a significant increase to their regular dose of medication.

**Care after Death**
As with all deaths those left behind will need advice and support to undertake the practical tasks such as contacting a funeral director, registering the death and dealing with the deceased’s affairs. Thought should also be given to emotional and spiritual needs during bereavement and whether referral or signposting for structured bereavement support is required. The support needs of the staff involved should also be considered and debriefing and reflection should be available.
Acknowledgements
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These guidelines have been written and produced as part of a working group. Members include: Dr Sarah Kelt (Consultant in Palliative Care), Louise Massey (Palliative Care CNS), Lisa Cooper (Palliative Care CNS), Naveed Mustfa (Consultant in Respiratory Medicine) and Marie Mountford (Clinical Nurse Specialist non–invasive Ventilation).
References


Leicestershire and Rutherford MND Supportive and Palliative Care Group (2009) Guidelines for withdrawing Non-invasive Ventilation (NIV) in Patient’s with MND

GMC (2010) Treatment and care towards the end of life. good practice in decision making. London. GMC.
Process for Complete withdrawal of NIV

**Home**

**Patient is in preferred place of NIV withdrawal.**

**Hospice**

**Hospital**

**Involve:**
1. Carer/family
2. Patient's GP
3. Community palliative care consultant
4. Clinical nurse specialist – non invasive ventilation
5. Palliative care CNS/clinical champion

**Involve:**
1. Carer/family
2. Palliative care consultant in hospice
3. Clinical nurse specialist - non invasive ventilation
4. Hospice nurses
5. Patient's GP

**Involve:**
1. Carer/family
2. Respiratory consultant
3. Palliative care consultant
4. Clinical nurse specialist - non invasive ventilation
5. Palliative care CNS
6. Ward staff/nurses
7. Patient’s GP

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It is important that the patient, carer/family and the members of the MDT are aware of the plan for type of withdrawal and ensure all key members are in place and medications are available including oxygen

1. **Give STAT doses minimum of 10mg of Diamorphine, 10mg of Midazolam and 20mg Hyoscine Butylbromide IV/SC**
2. **Repeat this at 10-15 minute intervals**
3. **The patient should be settled and comfortable**

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Switch off ventilation and removal of mask by designated person

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Change over to 28% Oxygen

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Give IV/SC Diamorphine, Midazolam and Hyoscine Butylbromide PRN to ensure that patient is completely settled and comfortable

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If prolonged survival consider continuous infusion

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All staff involved in the process should remain until death occurs or confident that patient is settled and the family have the support that is needed
Process for weaned withdrawal of NIV

1. Patient is in preferred place of NIV withdrawal

Involve:
1. Carer/family
2. Patient’s GP
3. Community palliative care consultant
4. Clinical nurse specialist - non invasive ventilation
5. Hospice nurses
6. Patient’s GP

Involve:
1. Carer/family
2. Patient’s GP
3. Community palliative care consultant
4. Clinical nurse specialist - non invasive ventilation
5. Patient’s GP

Involve:
1. Carer/family
2. Palliative care consultant at hospice
3. Clinical nurse specialist - non invasive ventilation
4. Hospice nurses
5. Patient’s GP

It is important that the patient, carer/family and the members of the MDT are aware of the plan for type of withdrawal and ensure all key members are in place and medications are available including oxygen.

If patient is unsettled give a STAT IV/SC does of Diamorphine 10mg, Midazolam 10mg and Hyoscine Butylbromide 20mg and start a continuous infusion under the guidance of specialist palliative care team.

Only when patient is comfortable slowly reduce inspiratory pressures of NIV at machine at increments of 2-4cm.

After each reduction in pressure monitor for any signs of distressing symptoms and give IV/SC medication as needed.

Do not reduce pressures again until patient is settled. If more than two IV/SC bolus doses of medication are required to settle patient consult palliative care CNS and consider increasing sc pump.

Continue with the process until death occurs or the pressure on the NIV reaches 8cm of water.

Removal of mask by designated person and switch to oxygen at 28%.

All staff involved in the process should remain until death occurs or confident that patient is settled and the family have the support that is needed.