SPAGG

Coversheet for Specialist Palliative Audit and Guideline Group Agreed Documentation

This sheet is to accompany all documentation agreed by SPAGG. This will assist maintenance of the guidelines as well as demonstrating the governance process undertaken prior to members seeking local approval in their areas of work.

Document Title	Guideline for Withdrawal of Assisted Ventilation for Hospital Inpatients Outside of Critical Care Settings, and Patients In the Community Setting.
Document Date	March 2025
Document Purpose and Intended Audience	This guideline provides information on withdrawal of assisted ventilation in community-based patients and hospital in-patients undergoing tracheostomy ventilation, non-invasive ventilation via BIPAP or ventilatory support with CPAP, whatever the cause for ventilation initiation.
Authors	Current Review 2025 by Dr Nadia Khan and Tricia Evans. Previous authors in 2020 include Dr Kate Holyhead, Dr Milind Arolker, Dr Anna Lock, Dr Diana Kavanagh.
References	At end of document
Consultation Process	Discussed and ratified at SPAGG
Monitoring	Review by SPAGG
Review Date	March 2028
Approval Signatures:	
SPAGG chair	Dr Jon Tomas
SPAGG secretary	Dr Hannah Fox
Date Approved by SPAGG: 12th March 2025	

Date submitted to Area Prescribing Committee:

Withdrawal of Assisted Ventilation for Hospital Inpatients Outside of Critical Care Settings, and Patients In the Community Setting.

Summary of change/process:

The guideline has been made more comprehensive, remit has been extended to cover community-setting assisted ventilation withdrawal, and guidance for subcutaneous sedation has been included. Documentation aid, risk assessment example and audit tool have been added.

Contents

1. Introduction

This guidance covers both community-based patients and hospital in-patients undergoing tracheostomy ventilation, non-invasive ventilation via BIPAP or ventilatory support with CPAP, whatever the cause for ventilation initiation.

Assisted ventilation withdrawal may take place either due patient request, or because a patient lacks capacity and withdrawal of treatment is deemed to be a best interests' decision. Some patients will gradually reduce their use of ventilation due to their choice or poor tolerance, and therefore not require a formal withdrawal process to be undertaken. In addition, assisted ventilation may be viewed as a palliative treatment for dyspnoea – and can be used alongside other palliative symptom control measures. As such, patients can and do die peacefully with assisted ventilation in place.

An individualised approach is necessary to undertake a safe, effective, and well-supported withdrawal of assisted ventilation. A procedural aid is provided to support clinician's clinical reasoning, ensure a shared-decision approach with patients, and ensure a carefully planned withdrawal is undertaken to minimise distress (appendix 1).

2. Roles and Responsibilities

Multidisciplinary Team	• To understand the guidelines and utilise as needed. • Ensure multi-disciplinary approach to decision making. • Ensure patient and family fully involved and informed throughout • Ensure when withdrawal agreed that it's done in a planned manner with sufficient resources (staffing and medication) to avoid suffering. • Ensure sufficient senior support available at the time withdrawal is planned. • Report any concerns of their own or others competence to their line manager
Specialist Palliative Care Team	• To provide help and advice to Multidisciplinary Team when support is required with a complex case including psychological support for staff. • In community this will usually consist of a Community palliative care consultant and / or palliative care clinical nurse specialist.
Line managers/ Service Leads	• To ensure staff are appropriately trained and competent to carry out the clinical procedure • To ensure appropriate resources are available for the procedure to be conducted
Audit	• MDT or Specialist Palliative Care Team to collaborate with SPAGG regional audit on withdrawal of assisted ventilation (appendix 2)

3. Other Guidelines To Which This Guideline Relates

    - West Midlands Palliative Care Physicians Guidelines for the use of drugs in symptom control
    - SPAGG guidelines on prescribing anticipatory medications

4. Ethical, Emotional, Legal and Practical Considerations

4.1. Assisted ventilation as a 'serious medical treatment'

Assisted ventilation should be regarded as a 'Serious Medical Treatment', for which a decision to withhold or stop existing treatment, is a serious decision.

Characteristics of serious decisions include ones where:

1. There is a fine balance between the treatment's benefits, burdens, and risks.
2. The decision between the choices of treatments is delicately balanced.
3. What is proposed would be likely to involve serious consequences.
4. In emergency situations when urgent decisions are required, immediate action should be taken in the person's best interests.

4.2. Legal status of withdrawal of treatment

Withdrawal of treatment, even if the treatment is life-sustaining, is <u>not</u> equivalent to euthanasia or physician assisted suicide (where there is an intention to actively hasten a patient's death). Rather, the withdrawal of treatment allows the underlying disease to take its natural course.

4.3. Decision-making process for withdrawal of assisted ventilation

A patient with capacity to make such a decision may either refuse assisted ventilation or ask that it be withdrawn. A patient with capacity may also make an Advance Decision to Refuse Treatment (ADRT) to be implemented at a future point when capacity is lost and the specified circumstances for the refusal become applicable.

The Mental Capacity Act 2005 Code of Practice provides that there should be a presumption of capacity for decisions, until there is proof that there is no capacity.

In UK law a refusal of a medical treatment by a patient who has capacity for that decision, must be respected and complied with, even if to comply with this refusal could lead to significant harm to the patient, including to their death. To continue medical treatments that a patient does not want, is to give treatment without consent. This legally constitutes a criminal offence of battery or a tort in civil law, justifying financial compensation.

If there is no valid ADRT in place, nor an available Lasting Power of Attorney for Health and Welfare (LPAHW) appointed by the patient, the decision to withdraw a medical treatment from the patient who no longer has capacity is a 'best interests' decision. This should be shared and agreed between the clinical team and the Next of Kin (NOK), or Independent Mental Capacity Advocate (IMCA) in the absence of NOK.

The GMC guidance Treatment and Care Towards the End of Life: Good Practice In Decision Making (2022) provides more detail including how to conduct this decision making in the context of conflict, disagreement within the treating team or with the patient and/or their representatives, about withdrawing ventilation or with respect to mental capacity (appendix 3) and in particular the value of gaining a second opinion.

4.4. Emotional Considerations

The request for assisted ventilation withdrawal, and undertaking the actual process itself, can evoke a strong emotional response from all people involved- patients, family members and support network, and the clinical team who may have been providing care for a significant period. Emotional responses may centre around the grief of anticipated loss, questioning/disbelief, anger, guilt or moral distress. Physicians have reported anxiety and distress about the perception of withdrawing ventilation in a conscious patient who dies soon after the process. It is important to provide both family members and wider staff the appropriate support and opportunities to discuss the events with the professionals due to be involved in withdrawal of assisted ventilation. This may be provided by well-being / counselling / chaplaincy support, depending on the nature of emotional support need.

4.5. Practical considerations

4.5.1. Communication and discussion

Before ventilation is started, ideally discussions about potential future withdrawal should be had between the patient, their family and the multidisciplinary team- and continue throughout the duration of the illness.

When it has been decided to withdraw assisted ventilation, discussions should take place and include the individual patient, family and healthcare team members. The reasons for the decision should be discussed in a thorough and open manner, without coercion. Potential for alternative decisions, and minimising the impact on family members, should also be discussed. Further discussion prompts are given in Appendix 4.

4.5.2. Assisted ventilation withdrawal standards

a) Patients should be made aware they have the right to ask for ventilation withdrawal.

b) A senior clinician should lead the planning and coordination of withdrawal.

c) Withdrawal should take place within a few days of an affirmed request, ideally during working hours.

d) Symptoms of breathlessness and distress should be anticipated and effectively managed.

e) Family members should have appropriate support and opportunities to discuss the events with the professionals involved.

4.5.3. Sedation during the removal of assisted ventilation

It is reasonable to assume that most patients who are dependent on ventilatory support are likely to feel symptomatic rapidly during the withdrawal of treatment with symptoms of acute dyspnoea and distress. Symptom control in this patient group will therefore require proportionate sedation immediately prior to attempts to remove the assisted ventilation. For most patients, management with morphine and midazolam at total doses <20mg of each drug will be sufficient to ensure a symptom-controlled withdrawal from ventilatory support. Patients on pre-existing opioid/benzodiazepines may require higher doses than usual- support from the Palliative Care team should be sought.

If a patient can manage without ventilatory support for some time, then a different symptom management plan may be required, which should be discussed with the supporting specialist palliative care team.

Arguably intravenous (IV) administration of strong opioids and sedation gives the most control and responsiveness to symptoms. It is also easily titratable, as the response to the medication is visible within 15–30 seconds following administration.

The subcutaneous (SC) route may be appropriate for patients with no IV access, or if the ventilation withdrawal is taking place in the patient's home / community setting. The onset of sedation may take longer and be more variable- planned NIV withdrawal may therefore take a longer time than expected so ensure adequate staffing for withdrawal in the community setting is available.

To ensure ongoing symptom control further IV or SC bolus doses can be given during the process of ventilation withdrawal. A continuous subcutaneous infusion can be initiated after withdrawal, if the patient appears to be dying slowly. For assistance of syringe driver starting doses, contact the Specialist Palliative Care Team. Close symptomatic monitoring is required with prompt administration of further medication if required.

4.5.4. Hypoxia and the dying process after the removal of assisted ventilation

Hypoxia can develop rapidly following removal of assisted ventilation which may add to feeling of breathlessness and distress. Family should be informed prior to the process that their loved one may become rapidly cyanosed / change colour, and that the breathing pattern may change, become shallower before stopping. Palliative oxygen can be administered after treatment withdrawal via nasal cannula / tracheostomy. However, the routine monitoring of patient oxygen saturations in this setting is inappropriate.

It is difficult to predict how long people will survive off their ventilatory support. Some will die very quickly, for others it will be over a period of hours and sometimes even days. Patients dying during the withdrawal process have been reported. It is important to communicate this potential uncertainty to family members before the process is commenced.

5. Considerations for assisted ventilation withdrawal in the community

A full assessment of patients' capacity may require multiple assessments and discussions around decision making with the involvement of at least 2 senior health professionals and the patient's community palliative care nurse specialist. The General Practitioner and disease-specific specialists e.g. MND team should be involved in the decision-making process.

Documentation evidencing the decision-making process around assessment of withdrawal must be clear and sufficient. National and locally developed preferences of care documentation e.g. 'ReSPECT', 'My Care and me' should be identified and reviewed within the decision-making process alongside any formal ADRT.

Ensure effective communication with the patient's wider healthcare team regarding the decision and plans, to reduce the risk of uncoordinated care.

Family and carer distress may be a significant issue as ventilation is withdrawn in the home environment. This can be mitigated by providing clear communication before the process (description of what to expect), during (explanation), and proactively discussing the ethical and legal aspects with reassurance that withdrawal does not constitute euthanasia/assisted suicide.

Verification of death ought to complete immediately when it is appropriate to do so.

Immediate debrief with staff and family may be appropriate and can be planned.
An example of a risk assessment for community withdrawal of NIV is available in appendix 5.

6. Reference documents and bibliography

a. Association for Palliative Medicine (*APM*) guidance for the withdrawal of ventilatory support for patients with Neurological or neuromuscular disease (*2015*). https://apmonline.org/wp-content/uploads/2016/03/Guidance-with-logos-updated-210316.pdf

b. Treatment And Care Towards the End Of Life: Good Practice In Decision Making (*GMC, 2010*). https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life

c. Motor Neurone Disease Association: Information sheet 8C – withdrawal of ventilation with MND (2021). https://www.mndassociation.org/media/119

d. University Hospital North Staffordshire: Guidelines for withdrawing NIV at End of life. https://www.palliativedrugs.org/download/120517_Guidelines%20for%20withdrawing%20NIV.pdf

Appendix 1: Procedural Aid for the Withdrawal of Assisted Ventilation in Hospital In-Patients in Non-Critical Care Settings and Community Settings.

This document should be used in conjunction with the full SPAGG guidance document. It is suitable for patient's receiving ventilation via tracheostomy, BIPAP or CPAP. The doses of medications are for opioid and benzodiazepine naïve patients – seek Palliative Care advice if alternative medication dosages are needed, or there are concerns.

<table>
<tr><td colspan="2">1. Refer to initiation documentation in notes and identify the indication for ventilation, and patient characteristics</td></tr>
<tr><td colspan="2">2. Document in notes why the clinical team is considering withdrawal of ventilation in this patient? Document any that apply</td></tr>
<tr><td colspan="2">Unsuccessful weans – indicate how many</td></tr>
<tr><td colspan="2">Patient requesting withdrawal</td></tr>
<tr><td rowspan="4">Poorly- controlled symptoms despite treatment with ventilation.
Consider if ventilation is failing to meet original treatment aim or treatment burden is outweighing benefit.</td><td>Breathlessness</td></tr>
<tr><td>Panic / anxiety</td></tr>
<tr><td>CO_2 narcosis</td></tr>
<tr><td>Mask problems such as claustrophobia; facial trauma</td></tr>
</table>

Unmet spiritual needs of patient and/or loved one / family	
Resource allocation issues	

3. Capacity Assessment. Document one [Remember: facilitate communication (e.g., sign-language / interpreter)]

Patient has not lost capacity and no reason to doubt capacity	Loss of Capacity (one or more of cannot understand / cannot retain / cannot weigh information / cannot communicate)			
	Patient's valid (i.e., signed / dated) and applicable ADRT has become available indicating ventilation refusal even if life is threatened as a result	Withdrawal of ventilation is a best interests' decision…		
		…shared and agreed between clinical team and patient's lasting power of attorney for health & welfare	…shared and agreed between clinical team and NOK / family / loved one	…shared and agreed between clinical team and Independent Mental Capacity Advocate

4. Communication	Ensure documentation is clear which discusses shared decisions with the patient and/or family / carer regarding the withdrawal from ventilatory support. Describe and discuss the process of withdrawal with the patient and/or family / carer? Ensure there has been adequate time for all questions to be voiced and answered. If disagreement within the treating team or with the patient and/or their representatives, about withdrawing ventilation **stop** process and ensure these addressed before proceeding.
5. Treatment escalation plan and DNACPR	Review your patient's current management plan. Rationalise medications and discontinue unnecessary treatments e.g., NG feeding / antibiotic treatment etc. Ensure DNACPR decision and clear TEP/ReSPECT in place
6. Timing	Is the timing of the withdrawal appropriate for patient and/or family / carer and clinical staff? Withdrawal should take place within normal working hours
7. Supportive and spiritual care	Are there any spiritual care requests or requirements for your patient? Are there any other requests or requirements that can reasonably be fulfilled? E.g. certain people present, pets
8. Community healthcare team after death	In the community, arrange necessary review by GP if required to facilitate death certification and discuss cause of death, and organise who will undertake last offices and verification of death.

9. Assemble a team of members available for process (ideally 3/4)
- **Team must be in agreement that process is ethical and legal**
- **Set time for process and decide who will carry out the tasks:**

Preparation of environment, people present and equipment – medications available in appropriate quantities, oxygen, IV access +/- Saf-Ts (2), Needles and syringes, sharps box, syringe driver
Withdrawing telemetry / other continuous monitoring

Alteration of Ventilation settings, alarms / modes
Prescribing of end-of-life injectable controlled drugs (CDs)
Checking / signing out and preparation of CDs
Administration of CDs
Recording of CD administration and timings of administration during ventilation withdrawal process (appendix 4)
Oxygen delivery plan after ventilation withdrawn (e.g., placing nasal specula after mask taken off)
Facilitate electronic / video communication with off-site family / NOK
Provision of comfort and communication to family during the process; provision of spiritual or emotional support; provision of religious support / ministry

10.	**Practical Preparation**
Access	In hospital, ensure the patient has a patent cannula in situ (PICC or central line can also be used). In the community, ensure the site for subcutaneous bolus injections is prepared e.g. insertion of subcutaneous butterfly needle
Monitoring	Stop any unnecessary monitoring. Ensure alarms are silenced. Commence regular symptom observations
Ventilatory support	Ensure familiarity with the equipment. How the mask is removed, how to wean pressures, reducing or turning off the back up rate and silencing any alarms etc.

11.	**Withdrawal procedure**
Medication	Check patient **allergies**. Ensure an adequate supply of the required medications. Prepare morphine, midazolam and glycopyrronium medication
Initial sedation	**<u>Intravenous sedation</u>** **Make up in two separate syringes, clearly labelled.** **a.** 10 mg of morphine made up to 10 ml with water for injection making a **1 mg/ml morphine sulfate solution.** **b.** 10 mg midazolam made up to 10 ml of water for injection making a **1 mg/ml midazolam solution** Administer morphine and midazolam in **2 mg increments** (2 ml of solution), until the patient is sedated and unresponsive to voice or painful stimuli. IV medication take 15–30 seconds to take effect so the sedative effect can be seen quickly.
	<u>Subcutaneous sedation</u> Administer morphine 10-15mg SC and midazolam 5-10mg SC Repeat at 10-15 minute intervals if required until patient is settled and unresponsive to voice or painful stimuli. SC medication may take 20-30 minutes.

	If upper airway secretions, administer glycopyrronium 200mcg SC/IV or hyoscine butylbromide 20mg SC **Ensure you have enough medication available.** If a patient requires high initial doses of sedation, then ensure you have sufficient to give as repeated PRN boluses should dyspnoea or distress occur on down titration of the ventilatory support. **Do not attempt to withdraw ventilation on an insufficiently sedated patient**
Ventilator wean	Reduce the pressure settings by 50% or reduce the inspiratory pressure by 2cm to assess adequate sedation and prevent respiratory distress, then further reduce after assessing the patient's condition for 15 minutes. If symptoms appear uncontrolled, administer further stat morphine (2mg IV or 10mg SC) and midazolam (2mg IV or 10mg SC) until the patient appears settled and adequately sedated. **If the patient requires more than 2 repeated stat doses of morphine/midazolam and remains unsettled, then increase pressure settings and contact palliative care for advice with second line sedative agents.** **Do not attempt to wean further or withdraw ventilation if the patient is symptomatic / insufficiently sedated.**
Removal of mask	If the patient remains settled and sedated, then: Remove the mask and watch for any deterioration in symptom control. Manage this with further increments of morphine and midazolam as above, until the patient is settled
Oxygen	Apply oxygen via mask 28% or nasally 2-4l/min, depending on what is tolerated best by the patient. This is to provide symptom relief and to reduce visible cyanosis. **Oxygen saturations should not be tested.**
Consider a syringe driver	If a patient survives >1 hour after ventilation withdrawal, then contact Palliative Care to discuss the need for a syringe driver (or infusion pump if syringe driver unavailable)
Team	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

12.	**Care after death**
Documentation	Ensure a documented summary of the mediations administered and the reasons why e.g., uncontrolled symptoms. Which healthcare professional undertook which tasks e.g., medication administration, ventilator wean, time of death (Appendix 5)
Family support	Ensure family members have appropriate support and opportunities to discuss the events with the professionals involved.

Professional support	Members of the MDT may need a designated time to debrief about the events. Those involved with the withdrawal may need to reflect on the outcomes. What went well and what could be improved. For some being involved in an intervention that relates so closely in time to the patient dying requires more bespoke support. Consider clinical supervision for the team or as individuals.

Appendix 2 : SPAGG Audit Tool Withdrawal of Ventilation

Location of withdrawal	Home / Hospital (Critical care) / Hospital (Non-critical care)/ Hospice / Nursing home
Underlying medical condition for which assisted ventilation being given	
Documented reason for considering withdrawal of ventilation	Yes / no
Documented capacity assessment	Yes / no
If patient does not have capacity, documented that no LPA or ADRT in place	Yes / no / not applicable
Documented assessment of patient emotional / spiritual support needs	Yes / no
Documented assessment of family emotional / spiritual support needs	Yes / no
Patient on background opioid / benzodiazepine?	Yes (amount : / no)
Initial sedation given immediately prior to withdrawal process? **How much initial sedation given to settle patient, before withdrawal commenced?**	Yes / no Details of type and amount:
Subsequent amount of sedation required during the withdrawal process	Details of type and amount:
Subsequent amount of sedation required after ventilation fully withdrawn	Details of type and amount:
Additional strong sedation required? E.g. levomepromazine	Yes / no Details of type and amount:
Time to death after ventilation withdrawal (minutes)	
Staff distress at any point before, during or after ventilation withdrawal?	Yes / No

Appendix 3 : The Mental Capacity Act 2005 Code of Practice

In UK law a refusal of a medical treatment by a patient who has capacity for that decision, must be respected and complied with, even if to comply with this refusal could lead to significant harm to the patient, including to their death. To continue medical treatments that a patient does not want is to give treatment without consent and legally constitutes a criminal offence of battery or a tort in civil law justifying financial compensation.

The Mental Capacity Act 2005 Code of Practice provides that there should be a presumption of capacity for decisions, until there is proof that there is no capacity. As a matter of routine, it should be a practitioner familiar with the issues who is assessing capacity for decision making on those issues. Given the challenges in such decisions, and in the enactment of Advance Decisions Assessment of capacity to make the “serious decision” to stop ventilatory support is mandatory. To Refuse Treatment, it may sometimes be advisable to involve more than one appropriately trained clinician in assessing the patient’s capacity, and to gather feedback from the multi-professional team and the family regarding the consistency of the patient's wishes. Rarely this may require additional expertise such as that of a psychiatrist to determine whether there is an identifiable and treatable mental health disorder compromising capacity.

Appendix 4: Discussions with patient and family regarding withdrawal of NIV

Discussions ideally should include the specialist/community clinical nurse specialist 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. Discussion points to include:

1. *When does the patient wish to withdraw ventilation?*

   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 ventilation 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 withdraw*n?

   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 sleepier before withdrawal is started.

6. *Will the ventilation 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.

Appendix 5: Assisted Withdrawal Documentation Record (acknowledgement and permission for incorporation: Dr. Hazel Coop, UHCW)

<table>
<tr><td colspan="2">Patient demographics</td><td>Indication for NIV</td></tr>
<tr><td colspan="2"></td><td>Date of MDT discussion regarding withdrawal</td></tr>
<tr><td>Date and time of withdrawal</td><td colspan="2">Professionals and family present</td></tr>
<tr><td>Professional</td><td>Role</td><td>Syringe driver? Yes/No
If yes, date and time commenced and dose prior to withdrawal</td></tr>
<tr><td></td><td></td><td rowspan="5">Medication and dose in syringe driver</td></tr>
<tr><td></td><td></td></tr>
<tr><td></td><td></td></tr>
<tr><td></td><td></td></tr>
<tr><td></td><td></td></tr>
</table>

Stat medications during withdrawal				
Medication	Dose	Time administered	Reason administered	Effect
Any adverse events during withdrawal?				
Date and time of death				

Appendix 6: RISK ASSESSMENT NIV CARE PLAN – Example (acknowledgement and permission for incorporation: Tricia Evans, Compton Care)

Multiple Risks Assessment Form					
Service	**Medical / Nursing**	**Date of Assessment**		**Risk Assessor (s)**	

Activity	Significant Hazards noted	Who is at risk	Current Risk Control Measures	Estimated level of risk	Additional Actions needed	Level of risk after application of further	By whom/ when	Action Completed &
Planned withdrawal of NIV	Patient capacity to make fully informed decision	Patient	Full assessment of patients' capacity. Multiple assessments/ discussions by 2 senior health professionals and Palliative CNS. GP/Secondary care and specialists involved in discussions around		Full discussions with patient. Support patient to use communication device to ask questions. Allow sufficient			
Communication and decision making around withdrawal of NIV	Difficulty in communicating decisions (speech loss due to MND) or family influencing decision.	Patient	Patient using alphabet board independently with some verbal effort and gesturing with family support. Team giving enough time for visits to aid communication and felt able to understand patient effectively. No coercion apparent.		Full discussions with patient. Support patient to use of communication device to ask questions. Allow sufficient			
Documentation of decision making around planned withdrawal of NIV	Risk that documentation may be insufficient or unclear in evidencing decision making process around assessment of	Patient/ Palliative care service	Explored possibility of formal documentation of decisions in ADRT document. Patient preference was not to complete a formal ADRT. (Technical challenges and fatigue thought to be significant.) Patient deemed to have capacity through formal capacity		Escalated senior clinician and increased detail in documentation and capacity assessment including My care and me document.			

Planned withdrawal of NIV	Risk that the perception from patient/ family that withdrawal took a long time period after decision made.	Patient/ Family	Communication to patient and family that time needed: to assess ventilation effectiveness with involvement of specialist team to address symptoms with pharmacological and non-pharmacological measures to involve ventilation team and allow MDT discussion. to assess reversibility/		Ongoing communication of timeframes/ expectations. No indication that this is the case on last visit.			
Decision to support planned withdrawal of NIV	Risk that condition could, with time or continued NIV be partially reversible or improve to a tolerable level.		Repeated clinical assessments over a 3-week period, including experts from ventilation team. Ventilation team have assessed and maximised NIV to ensure ventilation was optimised and tolerable in terms of comfort (mask fitting etc). Regular assessment of symptoms and instigation of effective symptom control of breathlessness using syringe driver. MDT discussion including ventilation team discussing condition and		Continue to monitor patient up to planned date of withdrawal. Patient may die before NIV removed and can be supported to die with NIV mask in situ.			
Planned withdrawal of NIV	Risk of Ineffective communication with wider team around decision and	Patient/ wider MD	Communication of situation and plan to: GP/ DN/ ventilation team/ Social work.					

Planned withdrawal of NIV	Risk the planned withdrawal may not be able to go ahead on the scheduled day due to circumstances with staffing and/or equipment/ drugs	Patient/ family	Staffing: 2 Consultants available in case planned Consultant cannot attend. Consultant available for the initial 6 hours and then with breaks available until 10pm at which point on-call consultant would take over (not on site after 10pm). Palliative CNS planned to attend (2 sessions early/ late) Ventilation team able to support with team		Monitor staffing 23/11/20			
Planned withdrawal of NIV	The planned withdrawal may take a longer time than expected.	Patient/ Family	Senior cover arranged for 9am to 10pm on day of planned withdrawal. Senior consultant cover available after this day overnight remotely.					
Planned withdrawal of NIV	Family/carer distress. Staff distress	Patient/ Family Staff	Prior communication and clear descriptions of the process have been given. Plan to provide clear explanation throughout process of withdrawal. Clear explanation that withdrawal of NIV is ethical and legal and is not assisted suicide or euthanasia. Support before/during and after death for family. After death Verification with be done immediately when appropriate. Immediate debrief with staff and family.		Ongoing support and review since decision made.			
Planned withdrawal of NIV	Risk patient may die in distress and uncontrolled symptoms.		3-person approach planned (Consultant/ Palliative CNS/ Ventilation CNS), Weaning and use of sedation, along with potential use of oxygen (ordered) symptoms		Ongoing monitoring.			

Risk Assessment Matrix

Likelihood score	1	2	3	4	5
	Rare	Unlikely	Possible	Likely	Almost certain
5 Catastrophic	5	10	15	20	25
4 Major	4	8	12	16	20
3 Moderate	3	6	9	12	15
2 Minor	2	4	6	8	10
1 Negligible	1	2	3	4	5

1-3	Low Risk	Monitor Controls
4-6	Moderate Risk	Proceed with Care
8-12	High Risk	Review Regularly
15-25	Extreme Risk	Escalate Risk To Senior Management

Likelihood score	1	2	3	4	5
Descriptor	Rare	Unlikely	Possible	Likely	Almost certain

Frequency How often might it/does it happen	This will probably never happen/recur	Do not expect it to happen /recur but it is possible it may do so	Might happen or recur occasionally	Will probably happen/ recur but it is not a persisting issue	Will undoubtedly happen/recur, possibly frequently

Consequence:

Level	Descriptor	Actual or potential impact on individual
5	Catastrophic	Incident leading to death, multiple permanent injuries or irreversible health effects. An event which impacts on a large number of patients. Major structural damage. Senior management overview.
4	Major	Major injury leading to long-term incapacity/disability. Requiring time off work for more than 14 days or increase in length of hospital stay for 15 days.
3	Moderate	Moderate injury requiring professional intervention. Requiring time off work for 7-14 days or increase in length of hospital stay by 4-15 days. RIDDOR reportable incident.
2	Minor	Minor injury or illness, requiring minor intervention. Requiring time off work for up to 7 days or increase in length of hospital stay by 1-3
1	Negligible	Minimal injury requiring no/minimal intervention or treatment. No time off work.

Risk Assessment Communication Record:

I have read and understood this risk assessment and am aware how to raise any concerns or changes in process to my line manager or safety representative, which may invalidate this risk					
Name: (PRIN		Sign:		Date:	
Name: (PRIN		Sign:		Date:	
Name: (PRIN		Sign:		Date:	
Name: (PRIN		Sign:		Date:	
Name: (PRIN		Sign:		Date:	
Name: (PRIN		Sign:		Date:	
Name: (PRIN		Sign:		Date:	
Name: (PRIN		Sign:		Date:	