



# 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.

<b>Document Title</b>	<b>Withdrawal of assisted ventilation for hospital inpatients outside of critical care settings/ICU</b>
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## Withdrawal of Assisted Ventilation for Hospital Inpatients Outside of Critical Care Settings / ICU

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# CLINICAL GUIDELINE

## Withdrawal of Assisted Ventilation for Hospital Inpatients Outside of Critical Care Settings / ICU

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## 1. INTRODUCTION

This guidance covers hospital in-patients undergoing tracheostomy ventilation and non-invasive ventilation via BIPAP or ventilatory support with CPAP outside of the Critical Care setting whatever the cause of the initiation of their ventilation.

An Individualised approach is necessary for each patient. Two “Decision Aids” – one for initiation of ventilation treatment and one for treatment withdrawal (**Appendices 2 and 3**) - are provided to support healthcare clinicians’ clinical reasoning in this area which includes a step by step approach to the use of injectable strong opioids and sedatives when withdrawing ventilation treatment.

Decisions to withdraw ventilation must always be planned and carefully made. During particular events such as the coronavirus pandemic there may be unprecedented number of patients and pressure on resources.

Withdrawal will be either at patient request, or because a patient lacks capacity and withdrawal of treatment is felt 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.

## 2. ETHICAL, LEGAL AND PRACTICAL CONSIDERATIONS

This section consolidates guidance from four resources;

- [Association for Palliative Medicine](#) (APM) guidance for the withdrawal of ventilatory support for patients with Neurological or Neuromuscular disease (2015).
- [Treatment And Care Towards The End Of Life](#): Good Practice In Decision Making (GMC, 2010).
- [End of Life Care and human rights](#): a practitioner’s guide (accessed April 2020).
- [COVID-19 – ethical issues](#). A guidance note (British Medical Association, 2020).

## 3. VENTILATION IS A TREATMENT

Decisions to initiate and to withdraw ventilation must be considered a “serious” decision.

1. Assisted ventilation, whether invasive and delivered through a tracheal tube, or non-invasive and delivered by a mask or other equipment, is a medical treatment.
2. Withdrawal of treatment, even if the treatment is life-sustaining is not euthanasia or physician assisted suicide. Instead ventilation should be regarded as a ‘Serious Medical Treatment’ for which a decision to stop existing treatment or withhold is a “serious decision”. Characteristics of serious decisions include ones where:
  - a) There is a fine balance between the treatment’s benefits, burdens, and risks.
  - b) The decision between the choices of treatments is finely balanced.
  - c) What is proposed would be likely to involve serious consequences.
3. In emergency situations when urgent decisions are required, immediate action should be taken in the person’s best interests.

4. The GMC guidance *Treatment And Care Towards The End Of Life: Good Practice In Decision Making (2010)* 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 and in particular the value of gaining a second opinion.
5. In circumstances where the person with a patient's Lasting Power of Attorney for Health and Welfare or their next of kin does not agree with a clinical decision to withdraw assisted ventilation in best interests, it is important to explore the reasons for disagreement. If the disagreement is connected to a religious belief, it may be helpful to seek support from the chaplaincy service. Even where the disagreement is not connected to a religious belief or moral value, the chaplaincy service may be able to act as an independent mediator to help the family understand, come to terms with and accept the best interests decision. Every conversation with the family should be clearly documented in the medical records. If all efforts have been exhausted and no agreement can be reached, the clinical team should contact the Trust's Legal Services Department for further advice and support.

### ***3.1 The Mental Capacity Act (2005) Code of Practice***

1. 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.
2. Assessment of capacity to make the "serious decision" to stop ventilatory support is mandatory. 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 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.
3. A patient with capacity to make such a decision may either refuse assisted ventilation or ask that it be withdrawn.
4. 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.
5. If there is no *ADRT* signed by the patient, 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, shared and agreed between the clinical team and the Next of Kin (NOK), or independent mental capacity advocate (IMCA) in the absence of NOK.

### **3.2 The Human Rights Act (HRA)**

1. Following the abolition of the Liverpool Care Pathway, the recommendations in *More Care, Less Pathway (2013)* and the guidance described by *One chance to get it right (2014)* are in line with human rights principles. A key theme of these two documents is the requirement to support and involve patients in decisions about serious matters such as their end of life care, including treatments. Being approached to be involved in decisions about end of life care is the means by which a healthcare clinician can acknowledge a right to respect for private and family life – a right protected by Article 8 of the HRA.
2. The first part of article 8, a right to respect for “private life”, covers matters beyond conventional notions of ‘privacy’. It includes the protection of physical and mental well-being of patients, having choice and control over what happens (*including being involved in care and treatment decisions*), participation in the community and access to personal information. It is not an absolute right, and there may be reasons to restrict this right, such as the need to protect the rights of others or the wider community.

## **4. PRACTICAL CONSIDERATIONS**

1. Patients and clinicians should openly discuss their thoughts and concerns about assisted ventilation and quality of life, and the circumstances in which a life sustained by ventilatory support would become intolerable or unacceptable.
2. A patient who has refused or asked for withdrawal of treatment is entitled to palliative management of symptoms that arise from the treatment refusal or withdrawal.
3. Assisted ventilation may in itself be viewed as a palliative treatment of dyspnoea. The treatment can continue with other palliative measures for symptom control used as needed alongside the ventilation. Patients can and do die peacefully with ventilation in place.
4. These discussions involving the patient, their family and the multidisciplinary team preferably should begin before assisted ventilation starts and continue throughout the duration of the illness.
5. Discussion of factors leading to the decision to stop assisted ventilation should be open, without coercion and thorough, seeking to identify any potential for alternative decisions and to minimise the impact of such a decision on family members. Discussions should include the individual patient, family and healthcare team members.
6. Withdrawing assisted ventilation may lead to distressing symptoms that require anticipatory and timely treatment, using appropriate doses of medications such as injectable strong opioids & sedatives which are targeted at relieving these symptoms. As with all good practice in palliative care, the intent must be solely to avoid or ameliorate symptoms of discomfort or distress.

## 5. ETHICAL ISSUES RAISED BY THE COVID-19 PANDEMIC

1. The process presented in this guideline does not substitute other available guidance (*or process*) on the restriction of treatment options when resource allocation decisions become necessary. The BMA has reproduced an ethical framework, originally issued and revised by the Government in 2017, for helping clinicians “think through strategic aspects of decision-making during a pandemic”.
2. The Decision Aid for Initiation of Ventilation Treatment may influence the process of triage (*i.e. rationing scarce resources in emergency circumstances, for example by inviting the team to make transparent what duration of ventilation treatment will help determine on-going ventilation*), but it cannot be the sole guide, given the flexibility required of an organisation during an evolving pandemic, and a need to demonstrate fairness.
3. Instead the Decision Aid for Initiation of Ventilation Treatment guides the clinical team to consider the patient’s pathology, their capacity to consent to treatment, and how best to plan the review of ventilation treatment.
4. The Decision Aid for Ventilation Withdrawal encourages and permits transparency and open communication where resource allocation issues might arise during the delivery of care in the current pandemic.
5. Furthermore, the process of ventilation withdrawal presented in this guideline, if applicable and followed, should help all patients (*irrespective of whether resource allocation discussions affect them*) receive compassionate and relevant medical care and attention. This should include appropriate symptom management, and the best available end-of-life care, including provision of fundamental care in line with the absolute right to be free from inhuman or degrading treatment (*Article 3, protected by the HRA*).
6. Healthcare professionals find the process of withholding and/or withdrawal of treatment challenging, particularly where life is threatened; such instances in clinical care can test staff’s moral frameworks and staff’s understanding of legislative frameworks. For example, the right to life (*Article 2*) does not entitle anyone to compel healthcare professionals to continue life-prolonging interventions where this would expose the patient to inhuman or degrading treatment breaching Article 3.
7. Therefore the risks to Healthcare professionals’ well-being must be prioritised as their ability to respond during a pandemic will be dependent on this. The Decision Aid for Withdrawal of Ventilation treatment prompts the clinical team to think about second opinions, & ethics committee guidance.
8. Furthermore, the need for professional support for healthcare staff involved in withdrawal of treatment is itemised as the final task in [Appendix 3](#).

## 6. CHALLENGES IN THE WITHDRAWAL OF ASSISTED VENTILATION

The focus of assisted ventilation withdrawal has been in patients with deteriorating neuromuscular conditions, such as MND, with some work taking place for patients with chronic respiratory disease. The disease trajectory of these conditions has allowed time for thought and discussion, reaching conclusions and a plan in line with the patient’s wishes. The process and best practice developed by treating these patient groups will now need to be transferred to a different setting and disease trajectory.

Currently there is considerable variation in practice regarding the physical process of withdrawal but there is consensus on the standards;

1. Patients should be made aware that they have the right to ask to stop ventilation.
2. A senior clinician should lead the planning and coordination of the withdrawal.
3. Withdrawal should take place within a few days of an affirmed request.
4. Symptoms of breathlessness and distress should be anticipated and effectively managed.
5. Family members should have appropriate support and opportunities to discuss the events with the professionals involved.

### ***6.1 Basis for the Decision Aids***

- The team enacting the withdrawal must feel the process is ethical and legal.
- The first step in the process is establishing patient capacity. If a patient has capacity and has requested treatment withdrawal, this decision should be respected.
- If the patient lacks capacity, is there a specific and valid ADRT in place?
- Where the patient lacks capacity has the request for withdrawal come from a person with lasting power of attorney for health and welfare? The correct documents should be viewed and verified and the MDT should be in agreement that withdrawal of ventilatory support is in the patient's best interests.
- If the patient lacks capacity the decision-making process should be shared with family members / carers and the discussion should be documented clearly in the notes.
- The withdrawal process should be discussed with the patient and/or family members / carers and the discussion should be documented clearly in the notes.
- Once the decision has been made to withdraw treatment, consider reducing the amount of monitoring. Anything likely to alarm unnecessarily should be silenced.
- Focus should be on symptom control. Discontinue routine monitoring and observations and commence symptom observations.

There is considerable variation in the way assisted ventilation is withdrawn. This is likely to be due to variation in patient condition, physician preference and symptom burden. We know that coronavirus produces significant hypoxia, so 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 sedation prior to attempts to remove the assisted ventilation. If this is not the case and a patient can manage without ventilatory support for some time then a different management plan of their symptoms may be required. This could be discussed with the 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. This guidance recommends the use of IV administration of medication.

## **6.2 Spiritual Care**

Choosing to withdraw life sustaining treatment is an inexplicably difficult decision for a patient to make for themselves and the process lies personally, outside of medicine. Therefore, an appreciation of the things we can do to support a patient and their family's spiritual care when they are at their most vulnerable is essential. Spirituality encompasses religious beliefs but is significantly broader. Consider support from the Healthcare Chaplaincy Team; mouth care with favourite beverage; music; reviewing the infection control policy on visitors for COVID-19 suspect or positive patients at the end of life.

## **7. WHAT TO PLAN FOR**

1. Once the decision to withdraw assisted ventilation has been made, the withdrawal process should take place in a timely fashion, ideally within normal working hours.
2. The approach should be individually tailored to the patient and their circumstances.
3. One person should manage the ventilator settings, and another should administer the medications.
4. Review what medication the patient is already taking. A history of opioid or benzodiazepine use may affect palliative drug dosing. If a patient is already using high doses of opioid or benzodiazepine then contact the Specialist Palliative Care Team for further advice.
5. The ease of cannulation. While IV administration is preferable, patients can be managed without a cannula for drug administration if needed see [Appendix 4](#) for more information.
6. Familiarisation with the ventilator. It is vital to know how to turn off the alarm settings, turn off the machine and how to reduce pressure settings and back up rate.
7. The level of sedation needs to be adequate prior to ventilator removal. This can be quickly and effectively modified with IV administration of morphine and midazolam. The dose required for effective sedation varies greatly between patients and it is not possible to give absolutes when discussing drug doses. Most patients will be sedated with doses lower than 20mg of each drug for initial sedation (*and usually less than 10 mg of each drug is required*). If a patient does not appear to be sedated, contact the Specialist Palliative Care Team for advice on second line agents and further support. Do not attempt to remove ventilatory support in a patient who is insufficiently sedated.
8. For opioid naïve patients who are ventilator dependent make up two syringes with a solution of 10mg morphine and water for injection 1mg/ml and midazolam 10mg and water for injection 1mg/ml. Label both syringes.

9. Give increments of 2mg of each drug and watch the patient response. The patient should achieve a reduced conscious level with no response to voice or painful stimuli. Repeat the 2mg bolus doses until this has been achieved.
10. At this point the ventilation settings can be reduced by 50%. This is to test the adequacy of sedation. Observe the patient for 5 minutes. Further increments of 2mg of morphine and midazolam can be administered if the patient appears distressed
11. 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.
12. If the patient is stable symptomatically then further wean the ventilatory support and remove the mask or disconnect the ventilator. Continue watching for evidence of dyspnoea or distress which should be treated with PRN boluses of IV medication.
13. If the patient is not stable symptomatically, suspend withdrawal attempts. Increase the ventilator pressures and contact the Specialist Specialist Palliative Care Team for advice on second line sedative agents.
14. Hypoxia can develop rapidly, this may add to feelings of dyspnoea and distress. It can also be distressing for the family if their loved one becomes rapidly cyanosed. Oxygen can be administered after treatment withdrawal via nasal cannula or tracheostomy. It is used palliatively and the routine monitoring of patient oxygen saturations in this setting is inappropriate.
15. 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 days. Patients dying during the withdrawal process have been reported.
16. To ensure ongoing symptom control further bolus doses can be given, or a continuous subcutaneous infusion can be initiated. For assistance of syringe driver starting doses, contact the Specialist Palliative Care Team and also see guidance on the trust intranet here. Close symptomatic monitoring is required with prompt administration of further medication if required.

### **7.1 Care After Death**

After the patient's death family members should have appropriate support and if required opportunities to discuss the events with the professionals involved.

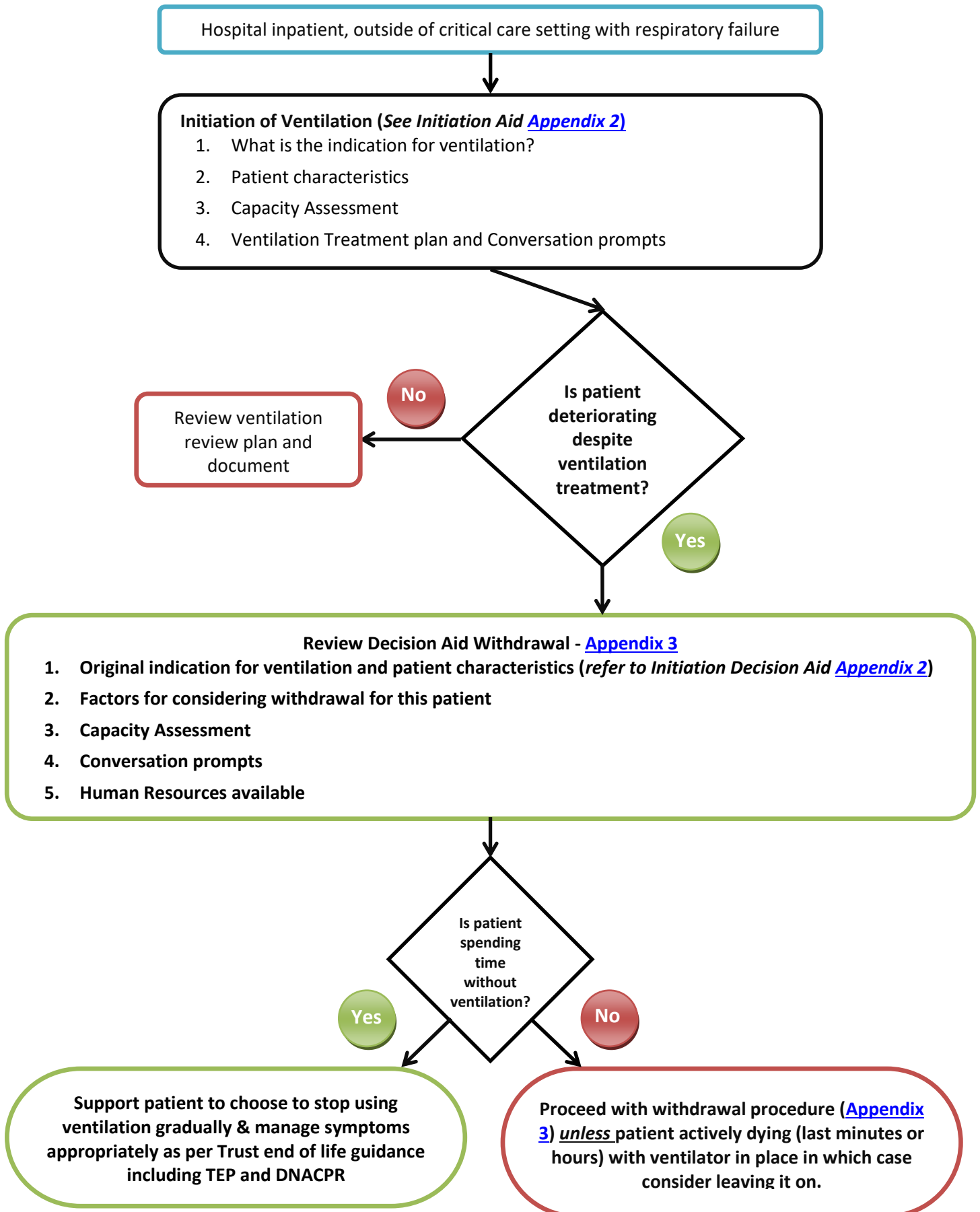
### **7.2 Health Care Professionals**

We know that withdrawal of assisted ventilation is an emotive topic. Physicians have reported anxiety and distress about the perception of withdrawing ventilatory support in a conscious patient, who dies soon after the procedure. If help, advice and/or support are required with a complex case then please contact the Specialist Palliative Care Team.

## 8. REFERENCE DOCUMENTS AND BIBLIOGRAPHY

- 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>
- 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>
- End of Life Care and human rights: a practitioner's guide (*accessed April 2020*). <https://www.bihl.org.uk/eolchumanrights>
- COVID-19 – ethical issues. A guidance note (*British Medical Association, 2020*). <https://www.bma.org.uk/media/2226/bma-covid-19-ethics-guidance.pdf>
- Respiratory Support Withdrawal (NIV CPAP HFNO) When Proven or Suspected COVID-19 University Hospital Leicestershire

# APPENDIX 1 Process Outline



## APPENDIX 2 Decision Aid: Initiation of Ventilation Treatment

1. Document in notes indication for ventilation in this patient			
Stepdown from Critical Care Services		Initiation of ventilation in HDU/ Ward/ ED settings	
With expectation of successful reversal of respiratory failure	Respiratory failure irreversible and patient deteriorating and then continue with Withdrawal tool	To support symptoms of chronic respiratory illness	Expectation of successful reversal of respiratory failure

2. Document in notes patient characteristics such as					
COVID-19 suspected/ positive	Neuromuscular disease (E.g. MND)	COPD/ Emphysema	Parenchymal lung disease (e.g. Fibrosis)	Chronic Suppurative lung disease (e.g. CF)	Other: (e.g. heart failure, Obesity Hyperventilation Syndrome, Obstructive Sleep Apnoea)

3. Assess & document capacity				
Patient retains capacity & no reason to doubt capacity	Loss of Capacity (one or more of cannot understand/cannot retain/cannot weigh information/ cannot communicate)			
	Initiation of ventilation is a best interests' decision...			
	...shared and agreed between clinical team & patient's lasting power of attorney for health & welfare	...shared and agreed between clinical team and NOK/ family/ loved one	...made urgently	

4. Ventilation Treatment Plan & Conversation prompts	Summarise in notes what you have discussed with patient/ family/ LPA/ NOK. If no opportunity for discussion, clarify plan for team
Aim of treatment (return to baseline use of domiciliary ventilator; to breathe without ventilator support).	<i>"Successful treatment would look like..."</i>
Anticipated time frame to achieve above aim (days; weeks)	<i>"We expect ventilation treatment to last..."</i>
Review plan – Tests required; frequency of review; what symptoms will guide review	<i>"We will review treatment based on..."</i>
Review notes for previous admissions for respiratory failure in order to review prognosis/prospects of survival	<i>"We have noticed previous admissions for respiratory failure, so we have to consider the possibility that treatment may not work this time round..."</i>
Treatment Escalation plan	<i>"We hope that ventilation treatment works, but it is possible it may not. In that case, we will discuss with our critical care colleagues OR In that case, we will switch the focus of care to comfort..."</i>

## APPENDIX 3 Withdrawal of Tracheostomy / Facemask Ventilation Treatment in Non-Critical Care Settings

This document should be used in conjunction with the full guidance document. It is suitable for patients receiving ventilation via tracheostomy, non-invasive ventilation and for ventilatory support with CPAP. On withdrawal of this support they will become symptomatic rapidly. This means proportionate sedation prior to ventilatory withdrawal is necessary to maintain adequate symptom control. These doses are for opiate and benzodiazepine naive patients. For most patient's management with morphine and midazolam at total doses <20mg of each drug will be sufficient to ensure a symptom-controlled withdrawal from ventilatory support. Support from the Palliative Care team should be sought if there are any concerns or a need for alternative sedating medication than those suggested below.

**1. Refer to initiation documentation in notes and identify the indication for ventilation, and patient characteristics**

**2. Document in notes why the clinical team is considering withdrawal of ventilation in this patient? Document any that apply**

Unsuccessful weans – indicate how many	
Patient requesting withdrawal	
Poorly-controlled symptoms despite treatment with ventilation.  Consider if ventilation is failing to meet original treatment aim (as summarised in Initiation Decision Aid or if treatment burden is outweighing benefit).	Breathlessness
	Panic/anxiety
	CO2 narcosis
	Mask problems such as claustrophobia; facial trauma
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 & 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) & 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 & 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

<b>4. Communication</b>	<p>Ensure documentation is clear which discusses shared decisions with the patient and/or family/ carer regarding the withdrawal from ventilatory support.</p> <p>Has the process of withdrawal been described and discussed with the patient and/or family/carer? Ensure there has been adequate time for all questions to be voiced and answered.</p> <p>If disagreement within the treating team or with the patient and/or their representatives, about withdrawing ventilation <b>stop</b> process and ensure these addressed before proceeding.</p>
<b>5. Treatment escalation plan &amp; DNACPR</b>	<p>Review your patient's current management plan. Rationalise medications and discontinue unnecessary treatments e.g. NG feeding/ antibiotic treatment etc.</p> <p>Ensure in DNACPR and clear TEP in place</p>
<b>6. Timing</b>	<p>Is the timing of the withdrawal appropriate for patient and/or family/ carer and clinical staff? Withdrawal should take place within normal working hours</p>
<b>7. Supportive and spiritual care</b>	<p>Are there any faith requests or requirements for your patient? Are there any other requests or requirements that can reasonably be fulfilled? E.g. rapid release of body</p>

<b>8. Check sufficient team members available for process – agree and set time for process and decide who will carry out the tasks</b>
Withdrawing telemetry/other continuous monitoring
Alteration of Ventilation settings, alarms/modes
Prescribing of end of life injectable controlled drugs (CDs)
Checking/signing out & Preparation of CDs
Administration of CDs
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; provision of spiritual or emotional support; provision of religious support/ministry

<b>9.</b>	<b>Practical Preparation</b>
<b>Access</b>	Ensure the patient has a patent cannula in situ (PICC or central line can also be used)
<b>Monitoring</b>	Stop any unnecessary monitoring. Ensure alarms are silenced. Commence regular symptom observations
<b>Ventilatory support</b>	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.

<b>10.</b>	<b>Withdrawal procedure</b>
<b>Medication</b>	<p>Check patient <b>allergies</b>. Ensure an adequate supply of the required medications.</p> <p><b>Make up in two separate syringes</b></p> <p>a. 10mg of morphine made up to 10ml with water for injection making a <b>1mg/ml morphine sulfate solution</b></p> <p>b. 10mg midazolam made up to 10ml of water for injection making a <b>1mg/ml midazolam</b></p>

	<b>solution</b>
<b>Initial sedation</b>	Administer Morphine and Midazolam in <b>2mg increments</b> (2mls of solution), until the patient is sedated and unresponsive to voice or painful stimuli. IV drugs take 15-30 seconds to take effect so the sedative effect can be seen quickly. If doses >10mg of morphine and midazolam are required at initial sedation, please contact the palliative care team for potential second line agent advice. <b>Do not attempt to withdraw ventilation on an insufficiently sedated patient</b>
<b>Ventilator wean</b>	Reduce the pressure settings by 50% Assess patient condition for 15 minutes. If symptoms appear uncontrolled, administer 2mg increments of morphine and midazolam until the patient appears settled and adequately sedated. <b>If the patient requires &gt;20mg of morphine and midazolam (total dose) and remains unsettled, then increase pressure settings and contact palliative care for advice with second line sedative agents.</b> <b>Do not attempt to wean further or withdraw ventilation if the patient is symptomatic/ insufficiently sedated.</b>
<b>Removal of mask</b>	If the patient remains settled and sedated, then: Remove the mask and watch for any deterioration in symptom control. Manage this with further 2mg increments of morphine and midazolam until the patient is settled
<b>Oxygen</b>	Apply oxygen via mask or nasally, depending of what is tolerated best by the patient. This is to provide symptom relief and to reduce visible cyanosis. <b>Oxygen saturations should not be tested.</b>
<b>Consider a syringe driver</b>	If a patient survives >1hr after ventilation withdrawal, then contact Palliative Care to discuss the need for a syringe driver (or infusion pump if syringe driver unavailable)

<b>11.</b>	<b>Care after death</b>
<b>Documentation</b>	Ensure a documented summary of the medications administered and the reasons why e.g. uncontrolled symptoms. Which healthcare professional undertook which tasks e.g. medication administration, ventilator wean.  The time of death:
<b>Family support</b>	Ensure family members have appropriate support and opportunities to discuss the events with the professionals involved.
<b>Professional support</b>	Members of the MDT may need a 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 4 Alternative route of administration of medication if cannula not in place

For some people a cannula may not be desirable or possible and in this group the subcutaneous (SC) route can be used instead for medication in anticipation of symptoms and as respiratory support is stopped.

1. Follow the complete guidelines for *Withdrawal of Assisted Ventilation for Hospital Inpatients Outside of Critical Care Settings* to prepare and plan process.
2. Instead of intravenous medications prescribe:

a.	Morphine 5-10mg SC as needed	For pain/ breathlessness Alternative opioids may be appropriate & seek specialist advice if considering.
b.	Midazolam 5mg-10mg SC as needed	For distress
c.	Levomepromazine 5mg - 12.5mg SC as needed	For sedation.
d.	Hyoscine Butyl Bromide 20mg SC as needed	For secretions

3. Ensure two separate SC lines in situ: alternate site in case repeated doses are needed to help drug absorption.
4. Administer opioid and midazolam with aim for patient sedation starting with lower doses.
5. Assess for several minutes the level of sedation and repeat medications as needed at 10 minute intervals until patient is sedated and peaceful.
6. Return to '**ventilator wean**' section of Appendix 3 managing any deterioration in symptom control with further subcutaneous doses of morphine and midazolam until the patient is settled.