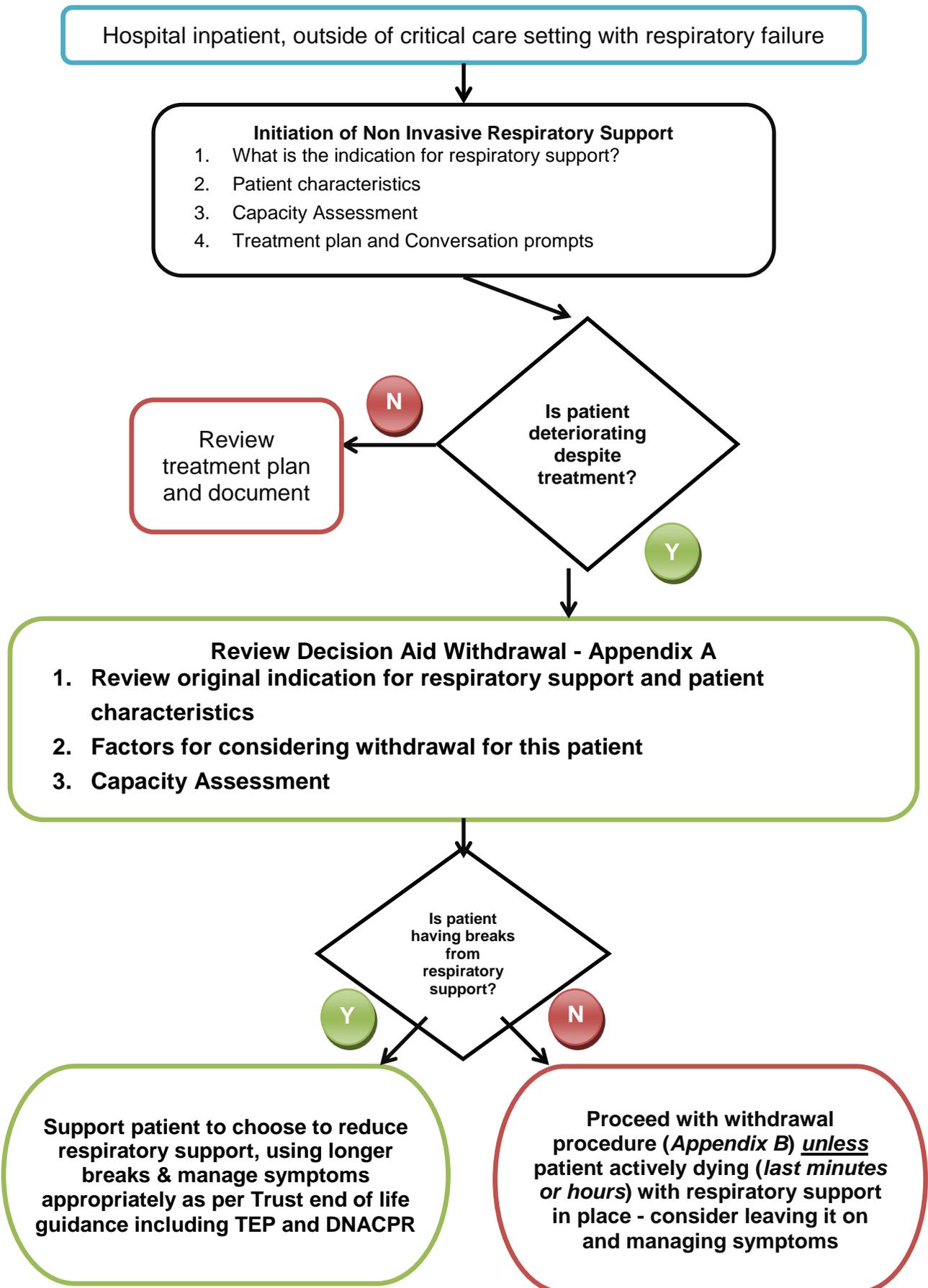


Withdrawal of Non-Invasive Respiratory Support for Hospital Inpatients in Non-Critical Care Settings Clinical Guideline

V1.0

March 2021

Summary



1. Aim/Purpose of this Guideline

- 1.1. Initiating and withdrawing respiratory support is a serious medical decision. The palliative focus of withdrawal has generally 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 illness trajectory.
- 1.2. In the context of acute respiratory failure, withdrawal of respiratory support may be necessary for patients with significant symptoms of breathlessness, and high oxygen requirements. This has become increasingly common due to the COVID-19 respiratory pandemic.
- 1.3. 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 ventilatory support (advance decision to refuse treatment).
 2. A senior clinician should lead the planning and coordination of the withdrawal.
 3. Withdrawal should take place within, at most, 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.
- 1.4. This guidance covers hospital in-patients undergoing respiratory support via NIV, CPAP and HFNO outside of the Critical Care setting **whatever the cause of the initiation of their ventilation.**
- 1.5. Decisions to withdraw ventilation must always be planned and carefully made. An individualised approach is necessary for each patient. A "Decision Aid" for treatment withdrawal (**Appendix A**) is provided to support healthcare clinicians' clinical reasoning in this area, including a step by step approach to the use of injectable strong opioids and sedatives when withdrawing ventilation treatment. It is expected the content of this tool will be documented clearly and methodically in the contemporaneous medical notes. They will form the basis of audit for safe and effective practice in this challenging area of care.

Data Protection Act 2018 (General Data Protection Regulation – GDPR) Legislation

The Trust has a duty under the DPA18 to ensure that there is a valid legal basis to process personal and sensitive data. The legal basis for processing must be identified and documented before the processing begins. In many cases we may need consent; this must be explicit, informed and documented. We cannot rely on opt out, it must be opt in.

DPA18 is applicable to all staff; this includes those working as contractors and providers of services.

For more information about your obligations under the DPA18 please see the *Information Use Framework Policy* or contact the Information Governance Team
rch-tr.infogov@nhs.net

2. The Guidance

2.1. Roles and Responsibilities

This is patient-focused decision, enacted by a multidisciplinary team. This team is likely to consist of a lead consultant responsible for the patients care, junior doctor team, nursing team, specialist nurses such as critical care outreach, respiratory trained physiotherapists. It should also include the family and those important to the patient including the ability to be present, if safe visiting allows at the point of withdrawal of treatment. It is not possible to specify the exact team but they should be competent, preferably during 'in hours' and experienced in this type of care. Support in or out of hours can be sought from the palliative care team.

2.2. Process Description

2.2.1. Decision to Withdraw Treatment

- 2.2.1.1. The team enacting the withdrawal must consider the process to be 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?
- 2.2.1.2. 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 respiratory support is in the patient's best interests.
- 2.2.1.3. 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.
- 2.2.1.4. The withdrawal process should be discussed with the patient and/or family members / carers and the discussion should be documented clearly in the notes.**

2.2.2. Ethical and Legal Considerations

- 2.2.2.1. Assisted ventilation, high flow nasal or continuous positive pressure oxygen support whether invasive e.g delivered through a tracheal tube, or non-invasive and delivered by a mask or other equipment, is a medical treatment.
- 2.2.2.2. 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 e.g. death.

2.2.2.3. In emergency situations, when urgent decisions are required, immediate action should be taken in the person's best interests.

2.2.2.4. 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.

2.2.2.5. 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 interest 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.

2.2.3. The Mental Capacity Act (2005) Code of Practice.

2.2.3.1. 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.

2.2.3.2. Assessment of capacity to make the "serious decision" to stop respiratory 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.

- 2.2.3.3. A patient with capacity to make such a decision may either refuse assisted ventilation or ask that it be withdrawn.
- 2.2.3.4. 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.
- 2.2.3.5. 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 where appropriate.

2.2.4. The Human Rights Act (HRA)

- 2.2.4.1. 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.
- 2.2.4.2. 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.

2.3. Ethical Issues Raised by the COVID-19 Pandemic

- 2.3.1. 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”.

- 2.3.2. The decision making process around initiating respiratory support may be influenced by the process of triage (i.e. rationing scarce resources in emergency circumstances, for example by inviting the team to consider the likely duration of respiratory support, to help determine an appropriate treatment plan), but it cannot be the sole guide, given the flexibility required of an organisation during an evolving pandemic, and a need to demonstrate fairness.
- 2.3.3. The Decision Aid for Respiratory Support Withdrawal encourages and permits transparency and open communication where resource allocation issues might arise during the delivery of care in the current pandemic.
- 2.3.4. Furthermore, the process of treatment 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).
- 2.3.5. 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.
- 2.3.6. 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 Respiratory Support prompts the clinical team to think about second opinions, & ethics committee guidance.
- 2.3.7. As the pandemic has evolved so has treatment with the initial response for invasive ventilation now increased to include non-invasive ventilation, high flow nasal oxygen and CPAP treatments being used to support improvement.
- 2.3.8. Furthermore, the need for professional support for healthcare staff involved in withdrawal of treatment is itemised as the final task in **Appendix B**.

2.4. Practical Considerations

- 2.4.1. This guidance is for withdrawal using IV medication. Successful withdrawal can be achieved using subcutaneous administration. Please contact palliative care for advice if this is needed.

- 2.4.2. Patients and clinicians should openly discuss their thoughts and concerns about assisted ventilation/HFNO/CPAP and quality of life, and the circumstances in which a life sustained by respiratory support would become intolerable or unacceptable.
- 2.4.3. 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.
- 2.4.4. **Respiratory support 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. Patients can, and do, die peacefully with respiratory support in place.
- 2.4.5. These discussions involving the patient, their family and the multidisciplinary team preferably should begin before respiratory support starts and continue throughout the duration of the illness.
- 2.4.6. Discussion of factors leading to the decision to stop respiratory support 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.
- 2.4.7. Withdrawing respiratory support 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.

2.5. **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 Spiritual Care Team** available 24/7 via switchboard). Mouth care with favourite beverage; music; reviewing the infection control policy on visitors for COVID-19 suspected or positive patients at the end of life.

2.6. **Withdrawal process and symptom control device**

- 2.6.1. There is considerable variation in the way respiratory support 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 respiratory 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 withdraw respiratory support. **If this is not the case and a patient can manage without respiratory support for some time, a different management plan of their symptoms may be required. This may involve commencing a syringe driver prior to attempts to reduce or withdraw ventilator support.**

This should be done in consultation with the Palliative Care Team, who are available 7 days 8-4 on bleep 3055 or at any time 24/7 via the Hospice advice line on 01736 757707

- 2.6.2. **Withdrawal using Intravenous medication and pre-sedation. Where IV access is not possible, consider the use of subcut medications for sedation. Please call Palliative Care for advice if necessary.**
- 2.6.2.1. Once the decision to withdraw respiratory support has been made, the withdrawal process should take place in a timely fashion, ideally within normal working hours.
 - 2.6.2.2. The approach should be individually tailored to the patient and their circumstances.
 - 2.6.2.3. One person should manage the ventilator/machine settings, and another should administer the medications. 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.
 - 2.6.2.4. 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 Palliative Care Team for further advice.
 - 2.6.2.5. **This guidance is for patient who are not already taking large doses of opioids or benzodiazepines. If this is the case the patient is likely to need larger doses than those prescribed here and potentially second line agents.** Contact palliative care for advice. Do not attempt a withdrawal until you are happy with the medication dosing and agents required.
 - 2.6.2.6. For patients who are dependent on respiratory support (e.g. those with high oxygen / pressure support requirements), IV administration is preferable.
 - 2.6.2.7. The level of sedation needs to be adequate prior to support 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 20 mg 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 Palliative Care Team for advice on second line agents and further support.

- 2.6.2.8. Do not attempt to remove respiratory support in a patient who is insufficiently sedated. The aim is to avoid symptoms of agitation, distress and discomfort.
- 2.6.2.9. **For opioid naïve patients who are dependent on their ventilator support** make up two syringes with a solution of 10 mg morphine and water for injection 1 mg/ml and midazolam 10mg and water for injection 1 mg/ml. Label both syringes clearly including time drawn up as they will be used for titration of symptom to dose. The syringes once drawn up should remain with the clinician administering and be safely disposed of by them with the dose given recorded in the ward CD record.
- 2.6.2.10. Give increments of 2 mg 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.
- 2.6.2.11. At this point the respiratory support settings can be reduced.
 - a) For NIV, reduce pressure support in 50% increments until symptom controlled removal is possible.
 - b) For CPAP/HFNO, reduce the oxygen concentration incrementally over 10 minutes, to as low as possible with symptom control. If this is a FiO₂ which requires mask or nasal cannula, obtain appropriate mask/specs for use post removal. Then reduce flow in 5L increments to 20 L/min. Observe the patient for a further 5 minutes. This is to test the adequacy of sedation.
- 2.6.2.12. The above are suggested withdrawal processes but each patient's needs are individual and senior respiratory staff may guide reduction using different increments and timings according to patient need.
- 2.6.2.13. Further increments of 2mg of morphine and midazolam can be administered if the patient appears distressed.
 1. 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 respiratory support.
 2. If the patient is stable symptomatically, then further wean the respiratory 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.

3. **If the patient is not stable symptomatically, suspend withdrawal attempts.** Increase the ventilator pressures/CPAP/HFNO to the last effective level and contact the Palliative Care Team (24/7) for advice on second line sedative agents.
4. 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 Venturi mask. It is used palliatively and the routine monitoring of patient oxygen saturations in this setting is inappropriate. The trust symptom control observations chart should be used.
5. It is difficult to predict how long people will survive off their respiratory 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.
6. If a patient survives off their ventilatory support for an hour, a syringe driver should be commenced to ensure ongoing symptom control. Doses will be based on the amount needed for symptom control during the initial withdrawal. For assistance of syringe driver starting doses, contact the Palliative Care Team. Close symptomatic monitoring with prompt administration of further medication if required.

2.7. 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.

2.8. Health Care Professionals

We know that withdrawal of respiratory support is an emotive topic. Physicians have reported anxiety and distress about the perception of withdrawing respiratory 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 Supportive and Palliative Care Team.

2.9. Training/ Competence Requirements

This is a multidisciplinary topic and specific training is not possible. Those sharing these decisions should be skilled, confident and able to enact the principles and activities involved in this guidance. Experiential learning from respiratory and palliative care senior medical staff will be key to model shared decision making and appropriate wellbeing safety after an episode of withdrawal.

3. Monitoring compliance and effectiveness

Element to be monitored	Impact on management of end of life care
Lead	Mortality review lead
Tool	This will be monitored through the picking up of any quality/safety issues in Mortality Reviews (SJR) recorded on a WORD or Excel template.
Frequency	Picked up via Medical Examiners and mortality review process
Reporting arrangements	Via mortality review committee
Acting on recommendations and Lead(s)	As above
Change in practice and lessons to be shared	As above

4. Equality and Diversity

4.1. This document complies with the Royal Cornwall Hospitals NHS Trust service Equality and Diversity statement which can be found in the ['Equality, Inclusion & Human Rights Policy'](#) or the [Equality and Diversity website](#).

4.2. Equality Impact Assessment

The Initial Equality Impact Assessment Screening Form is at Appendix 2.

Appendix 1. Governance Information

Document Title	Withdrawal of Non-Invasive Respiratory Support for Hospital Inpatients in Non-Critical Care Settings Clinical Guideline V1.0		
This document replaces (exact title of previous version):	New Document		
Date Issued/Approved:	27 th January 2021		
Date Valid From:	March 2021		
Date Valid To:	March 2024		
Directorate / Department responsible (author/owner):	Dr Carolyn Campbell, Consultant in Palliative Medicine Dr Jonathan Myers, Consultant in Respiratory medicine		
Contact details:	01736 759070		
Brief summary of contents	This guideline supports staff involved in planned withdrawal of non-invasive ventilation at end of life to ensure safe and ethical practice and appropriate support for patients, family and staff		
Suggested Keywords:	NIV, withdrawal, end of life		
Target Audience	RCHT	CFT	KCCG
	✓		
Executive Director responsible for Policy:	Medical Director		
Approval route for consultation and ratification:	Palliative Care Governance group Respiratory Team Governance group Clinical Effectiveness Group		
General Manager confirming approval processes	Louise Dickinson Deputy Director of Nursing Midwifery and AHPs		
Name of Governance Lead confirming approval by specialty and care group management meetings	Louise Dickinson Deputy Director of Nursing Midwifery and AHPs		
Links to key external standards	None required		
Related Documents:	None required		
Training Need Identified?	No		
Publication Location (refer to Policy on Policies – Approvals and Ratification):	Internet & Intranet	✓	Intranet Only
Document Library Folder/Sub Folder	Clinical / Palliative and End of Life Care		

Version Control Table

Date	Version No	Summary of Changes	Changes Made by (Name and Job
January 2021	V1.0	Initial issue	Dr Carolyn Campbell, Consultant in

All or part of this document can be released under the Freedom of Information Act 2000

This document is to be retained for 10 years from the date of expiry.

This document is only valid on the day of printing

Controlled Document

This document has been created following the Royal Cornwall Hospitals NHS Trust Policy for the Development and Management of Knowledge, Procedural and Web Documents (The Policy on Policies). It should not be altered in any way without the express permission of the author or their Line Manager.

Appendix 2. Equality Impact Assessment

Section 1: Equality Impact Assessment Form						
Name of the strategy / policy / proposal / service function to be assessed Withdrawal of Non-Invasive Respiratory Support for Hospital Inpatients in Non-Critical Care Settings Clinical Guideline V1.0						
Directorate and service area: Palliative Care			Is this a new or existing Policy? New			
Name of individual/group completing EIA Dr Carolyn Campbell, Consultant in Palliative Medicine			Contact details: 01736 759070			
1. Policy Aim Who is the strategy / policy / proposal / service function aimed at?		Medical and nursing staff on respiratory ward				
2. Policy Objectives		To support staff in the withdrawal of non-invasive ventilation at end of life				
3. Policy Intended Outcomes		Good quality end of life care for patients with appropriate support to families and staff				
4. How will you measure the outcome?		Mortality review				
5. Who is intended to benefit from the policy?		Patients, families, staff				
6a). Who did you consult with?		Workforce	Patients	Local groups	External organisations	Other
		yes	No	no	yes	
b). Please list any groups who have been consulted about this procedure.		Please record specific names of groups: Policy adapted from Somerset NHS trust				
c). What was the outcome of the consultation?		n/a				

7. The Impact				
Please complete the following table. If you are unsure/don't know if there is a negative impact you need to repeat the consultation step.				
Are there concerns that the policy could have a positive/negative impact on:				
Protected Characteristic	Yes	No	Unsure	Rationale for Assessment / Existing Evidence
Age		no		The decision to withdraw NIV should always be made by a senior clinician with appropriate consultation with patient (if capacity) and family. It will be based on response to treatment and likely clinical outcome rather than age. This guidance supports the process of withdrawal after that decision has been made
Sex (male, female non-binary, asexual etc.)		no		
Gender reassignment		no		
Race/ethnic communities /groups		no		
Disability (learning disability, physical disability, sensory impairment, mental health problems and some long term health conditions)		no		As above..
Religion/ other beliefs		no		
Marriage and civil partnership		no		
Pregnancy and maternity		no		
Sexual orientation (bisexual, gay, heterosexual, lesbian)		no		
<p>If all characteristics are ticked 'no', and this is not a major working or service change, you can end the assessment here as long as you have a robust rationale in place.</p> <p>I am confident that section 2 of this EIA does not need completing as there are no highlighted risks of negative impact occurring because of this policy.</p>				
Name of person confirming result of initial impact assessment:				
<p>If you have ticked 'yes' to any characteristic above OR this is a major working or service change, you will need to complete section 2 of the EIA form available here: Section 2. Full Equality Analysis</p> <p>For guidance please refer to the Equality Impact Assessments Policy (available from the document library) or contact the Human Rights, Equality and Inclusion</p>				

Lead debby.lewis@nhs.net