

# Withdrawal of Assisted Ventilation at the Request of a Patient : Audit of process and outcomes

**Association for Palliative Medicine of Great Britain and Ireland.  
November 2015**

## **Background**

The purpose of this audit is to provide information that can lead to the improvement of care for patients and their families.

Whilst the Guidance is specifically for patients with MND, there is potential that the principles and specifics may be applicable to patients with other conditions causing respiratory failure and for this reason the data collection seeks to include any ventilator-dependent patient who requests that their assisted ventilation be stopped. It is hoped that this may inform guidance for other populations in the future.

This includes patients with:

- Motor Neurone Disease
- Chronic respiratory disease
- Duchene muscular dystrophy
- spinal injury
- other neuro-muscular and lung pathologies

The data will be analysed by a joint audit group including members of the Association for Palliative Medicine, British Thoracic Society, Home Ventilation UK, and Association of British Neurologists, and reported as anonymised information that can inform guidance and practice. Summarised, anonymised benchmarking data will be available to individuals and professional organisations. Non-attributable information may also be submitted for publication in peer-reviewed clinical journals.

## **Drug regime for the management of symptoms**

As part of developing guidance, we want to understand in as much detail as possible the drugs and the doses utilised in managing the symptoms related to withdrawing assisted ventilation. This will not be the same for each patient, but we need to understand the breadth of practice and how practice relates to outcomes.

We would be grateful if you would try to provide information for the following questions as best you can, with as many comments/provisos/qualifiers as you feel you need.

Your personal details will be used only to provide you with reports and benchmarking data. All reports will be anonymised and all publications non-attributable.

Word and spreadsheet versions of the form are available from [Office@compleat-online.co.uk](mailto:Office@compleat-online.co.uk)

The completed audit form should be sent to [LAR.ventilation@nhs.net](mailto:LAR.ventilation@nhs.net)

Or by post to:

Professor Christina Faull, Chair of the joint audit group,  
LOROS , Groby Road, Leicester LE3 9QE  
Or Fax 0116 231 8457

# Withdrawal of Assisted Ventilation at the Request of a Patient:

## Audit of process and outcomes

Your name:

Your job/role:

Your email:

### Section 1: Background Information about the patient

1.	Age of patient (tick one)	<30 30–50 51–70 >70
2.	Sex (tick one)	Male Female
3.	Diagnosis (tick one)	MND COPD DMD Cervical spinal cord injury Other (specify)
4.	Date of death	MM/YYYY
5.	What type of assisted ventilation was withdrawn? (Tick one.)	NIV (mask/non-invasive ventilation) IV (ventilation via tracheostomy)
6.	How long had the patient been on this type of assisted ventilation? (Tick one.)	>1 year 6 months–1 year 1–6 months <1 month
7.	Where did the withdrawal take place? (Tick one.)	Home Hospice Hospital (specify type of ward) Care Home
8.	Did the patient have capacity to make the withdrawal decision, or was this carried out as part of an ADRT (advance decision to refuse treatment) or 'best interests' decision?	Capacity ADRT Best interests decision
9.	Which doctor(s) had discussed and agreed with the patient and family the decision to withdraw assisted ventilation? (Tick all that apply.)	GP Cons Neuro Cons Pall Med Cons Resp/Home Vent Team Other (specify)

### Section 2. Information about the clinical picture in the day before assisted ventilation was withdrawn

10.	How many hours a day was ventilation in use (tick one)?	Overnight only <16 hours/day 16–22 hours/day >22 hours/day N/A
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11.	How long could the patient manage without assisted ventilation support? (Tick one.)	Cannot manage at all A few minutes Up to an hour A few hours									
12.	How did the patient communicate in their last days? (Tick one.)	Speech Eye movements Writing/keyboard They could not Other (specify)									
13.	What was the patient's level of independence and function? (Tick one.)	Able to walk Mobile with use of wheelchair Bed- or chair-bound									
14.	Could the patient use their hands for any tasks? (Tick one.)	Yes No									
15.	What was the level of consciousness in the last days before withdrawal was commenced? (Tick one.)	Fully <b>A</b> lert Drowsy, responding to <b>V</b> oice Very drowsy, responding to touch/ <b>P</b> ain <b>U</b> nresponsive N/A (locked in state)									
16.	In your assessment, what symptoms was the patient experiencing on the assisted ventilation in their last days? (Grade each 0–10.)	Breathlessness: Anxiety: Distress: Other (specify):									
17.	What were the ventilator settings (prior to the withdrawal process)? (Fill as applicable.)	<table border="1"> <tr> <td>Mode of Ventilation</td> <td>Pressure control Pressure support Other</td> </tr> <tr> <td>IPAP</td> <td>cm H2O</td> </tr> <tr> <td>EPAP</td> <td>cm H2O</td> </tr> <tr> <td></td> <td></td> </tr> </table>	Mode of Ventilation	Pressure control Pressure support Other	IPAP	cm H2O	EPAP	cm H2O			
Mode of Ventilation	Pressure control Pressure support Other										
IPAP	cm H2O										
EPAP	cm H2O										
18.	Was the patient already on an infusion (syringe driver) before the withdrawal of assisted ventilation was planned? (not started as part of the withdrawal plan. See Q21)	Yes No  If yes, specify details of drugs: Drug 1: Dose/24hr:  Drug 2: Dose/24hr:  Drug 3: Dose/24hr:									

19.	Before the withdrawal of assisted ventilation was planned, was the patient taking regular oral, transdermal or per gastrostomy opioid and/or benzodiazepine?	Yes No  If yes, specify details of drugs  Opioid: Dose/24hr  Benzodiazepine: Dose/24hr
20.	Prior to the start of the withdrawal process (e.g. the night before the scheduled withdrawal) did you reduce the ventilator settings in anyway?	Yes No  If yes, please state in as much detail as possible what you did?
21.	Prior to the start of the withdrawal process (e.g. the night before the scheduled withdrawal) did you increase drugs for symptom management in anyway?	Yes No  If yes, please state in as much detail as possible what you did?

### Section 3. Information about the withdrawal

22.	What healthcare professionals were there to initiate the withdrawal (give professional role not names: e.g. GP, specialist ventilation nurse)?	
23.	Which healthcare professional took the lead in managing symptoms?	

24.	How long had the lead person known the patient for? (Tick one.)	Days Weeks Months Years
25.	Which healthcare professional specifically took the role of withdrawing the ventilator/taking the mask off? Or was this a family member?	
26.	What was the intention of symptom management before removing the assisted ventilation? (Tick one.)	To achieve total loss of awareness (sedation)  To make sleepy but still aware  No immediate symptom management was needed before withdrawing assisted ventilation  Other (specify)
27.	Did you give any medication (additional to any mentioned in Q18, Q19 or Q21 above) before you commenced withdrawal (i.e. anticipatory symptom management or sedation)?	First dose drug 1: Dose:  First dose drug 2: Dose:  First dose drug 3: Dose:  First dose drug 4: Dose:
28.	What route(s) for administration of drugs did you use? (Tick as applicable.)	IV SC IM PO Buccal Per-gastrostomy Rectal

29.	<p>Was further medication needed to manage symptoms <b>before</b> the assisted ventilation could be fully withdrawn? (Fill in each as needed.)</p>	<p>Drug 1: Number of additional doses: Total Dose (including first dose in Q27):</p> <p>Drug 2: Number of additional doses: Total Dose (including first dose in Q27):</p> <p>Drug 3: Number of additional doses: Total Dose(including first dose in Q27):</p> <p>Comments:</p>
30.	<p>How long before you withdrew assisted ventilation did you give the first dose of medication? (Add number of minutes/hours.)</p>	<p>Minutes Hours N/A</p>
31.	<p>How did you judge that symptoms were well enough managed to stop the assisted ventilation? (Tick one or add free text.)</p>	<p>The patient looked calm The patient was drowsy but awake The patient was asleep/lightly unconscious The patient did not respond to voice The patient did not respond to touch/pain The patient had lost corneal reflex Other</p>
32.	<p>Did you decrease the ventilator settings before completely stopping assisted ventilation?</p>	<p>Yes No</p> <p>If yes, please state in as much detail as possible what you did?</p>

33.	<p>Was further medication administered to manage symptoms <b>after</b> the assisted ventilation was withdrawn?  (Fill in separately for each time additional drug(s) were administered adding more similar records if required.)</p>	<p>1. Reason for further medication:  Drug(s) :  Doses:  Approximate time after assisted ventilation stopped:</p> <p>2. Reason for further medication:  Drug(s) :  Dose:  Approximate time after assisted ventilation stopped:</p> <p>3. Reason for further medication:  Drug (s):  Dose:  Approximate time after assisted ventilation stopped:</p> <p>Comments:</p>
34.	<p>Please summarise the drugs used to manage symptoms during withdrawal in Q27, Q29 &amp; Q33.</p>	<p>Drug 1:  Total Dose:</p> <p>Drug 2:  Total Dose:</p> <p>Drug 3:  Total Dose:</p> <p>Drug 4 :  Total Dose:</p>
35.	<p>Were there any symptoms that were very challenging to manage effectively during withdrawal?</p>	<p>Yes  No</p> <p>If yes, specify and comment:</p>
36.	<p>Did the patient die with the mask/interface still in place?</p>	<p>Yes  No</p>
37.	<p>Was the patient conscious after the assisted ventilation was withdrawn?</p>	<p>Yes  No</p>

38.	How long after the assisted ventilation was withdrawn did the patient live for? (Complete one.)	minutes hours days
39.	Were there any challenges related to family reactions during the withdrawal?	Yes No  If yes, please specify:
40.	What is your perception of what the experience was like for the family? (Tick one.)	Positive Difficult; beyond your expectation of normal grieving Frankly traumatic  Comments on issues/ how it could be improved:

#### Section 4. After the withdrawal

41.	Was there any immediate feedback from the family about the withdrawal if they were present, or anything they specifically commented on that may help others to know in the future?	Yes No  If yes, please specify:
42.	What was the experience like for you?	Positive Neutral Difficult Frankly traumatic  Please comment on what made the process difficult or traumatic for you:
43.	Is there anything you would do differently next time, anything that could have gone better, or any learning outcomes to share?	Yes No  If yes, please specify:
44.	How has this affected your confidence in this area of care? (Tick as applicable.)	My confidence has increased My confidence is unchanged My confidence has reduced I would prefer not to do it again



45.	Where there any issues that arose in the team debrief?	Yes No N/A no team debrief  If yes, then specify:
46.	Please add any other comments about the process of the withdrawal and symptom management	

**Thank you very much for taking part in this audit. Your contribution and time is very much appreciated.** Your personal details will be used only to provide you with reports and benchmarking data. All reports will be anonymised and all publications non-attributable.

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