**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**

|  |  |  |
| --- | --- | --- |
|  | Age of patient (tick one) | <30  30–50  51–70  >70 |
|  | Sex (tick one) | Male  Female |
|  | Diagnosis (tick one) | MND  COPD  DMD  Cervical spinal cord injury  Other (specify) |
|  | Date of death | MM/YYYY |
|  | What type of assisted ventilation was withdrawn? (Tick one.) | NIV (mask/non-invasive ventilation)  IV (ventilation via tracheostomy) |
|  | 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 |
|  | Where did the withdrawal take place? (Tick one.) | Home  Hospice Hospital (specify type of ward)  Care Home |
|  | 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 |
|  | 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 Information about the clinical picture in the day before assisted ventilation was withdrawn**

|  |  |  |
| --- | --- | --- |
|  | 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 |
|  | 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 |
|  | How did the patient communicate in their last days? (Tick one.) | Speech  Eye movements  Writing/keyboard  They could not  Other (specify) |
|  | What was the patient’s level of independence and function? (Tick one.) | Able to walk  Mobile with use of wheelchair  Bed- or chair-bound |
|  | Could the patient use their hands for any tasks? (Tick one.) | Yes  No |
|  | What was the level of consciousness in the last days before withdrawal was commenced? (Tick one.) | Fully **A**lert  Drowsy, responding to **V**oice  Very drowsy, responding to touch/**P**ain  **U**nresponsive  N/A (locked in state) |
|  | 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): |
|  | What were the ventilator settings (prior to the withdrawal process)? (Fill as applicable.) | |  |  | | --- | --- | | Mode of Ventilation | Pressure control  Pressure support  Other | | IPAP | cm H2O | | EPAP | cm H2O | |  |  | |
|  | 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: |
|  | 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 |
|  | 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? |
|  | 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**

|  |  |  |
| --- | --- | --- |
|  | What healthcare professionals were there to initiate the withdrawal (give professional role not names: e.g. GP, specialist ventilation nurse)? |  |
|  | Which healthcare professional took the lead in managing symptoms? |  |
|  | How long had the lead person known the patient for? (Tick one.) | Days  Weeks  Months  Years |
|  | Which healthcare professional specifically took the role of withdrawing the ventilator/taking the mask off?  Or was this a family member? |  |
|  | 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) |
|  | 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: |
|  | What route(s) for administration of drugs did you use? (Tick as applicable.) | IV  SC  IM  PO  Buccal  Per-gastrostomy  Rectal |
|  | Was further medication needed to manage symptoms **before** the assisted ventilation could be fully withdrawn?  (Fill in each as needed.) | Drug 1:  Number of additional doses:  Total Dose (including first dose in Q27):  Drug 2:  Number of additional doses:  Total Dose (including first dose in Q27):  Drug 3:  Number of additional doses:  Total Dose(including first dose in Q27):  Comments: |
|  | How long before you withdrew assisted ventilation did you give the first dose of medication? (Add number of minutes/hours.) | Minutes  Hours  N/A |
|  | How did you judge that symptoms were well enough managed to stop the assisted ventilation? (Tick one or add free text.) | 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 |
|  | Did you decrease the ventilator settings before completely stopping assisted ventilation? | Yes  No  If yes, please state in as much detail as possible what you did? |
|  | Was further medication administered to manage symptoms **after** the assisted ventilation was withdrawn?  (Fill in separately for each time additional drug(s) were administered adding more similar records if required.) | 1. Reason for further medication:  Drug(s) :  Doses:  Approximate time after assisted ventilation stopped:  2. Reason for further medication:  Drug(s) :  Dose:  Approximate time after assisted ventilation stopped:  3. Reason for further medication:  Drug (s):  Dose:  Approximate time after assisted ventilation stopped:  Comments: |
|  | Please summarise the drugs used to manage symptoms during withdrawal in Q27, Q29 & Q33. | Drug 1:  Total Dose:  Drug 2:  Total Dose:  Drug 3:  Total Dose:  Drug 4 :  Total Dose: |
|  | Were there any symptoms that were very challenging to manage effectively during withdrawal? | Yes  No  If yes, specify and comment: |
|  | Did the patient die with the mask/interface still in place? | Yes  No |
|  | Was the patient conscious after the assisted ventilation was withdrawn? | Yes  No |
|  | How long after the assisted ventilation was withdrawn did the patient live for? (Complete one.) | minutes  hours  days |
|  | Were there any challenges related to family reactions during the withdrawal? | Yes  No  If yes, please specify: |
|  | 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**

|  |  |  |
| --- | --- | --- |
|  | 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: |
|  | What was the experience like for you? | Positive  Neutral  Difficult  Frankly traumatic  Please comment on what made the process difficult or traumatic for you: |
|  | 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: |
|  | 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 |
|  | Where there any issues that arose in the team debrief? | Yes  No  N/A no team debrief  If yes, then specify: |
|  | 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.

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

Or by post or Fax to: Professor Christina Faull, Chair of the joint audit group,

LOROS, Groby Road, Leicester LE3 9QE (Fax: 0116 231 8457)