**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**

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|  | Age of patient (tick one) | <3030–5051–70>70 |
|  | Sex (tick one) | MaleFemale |
|  | Diagnosis (tick one) | MNDCOPDDMDCervical spinal cord injuryOther (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|  | What type of assisted ventilation was withdrawn?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 year6 months–1 year1–6 months<1 month |
|  | Where did the withdrawal take place? (Tick one.) | HomeHospiceHospital (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? | CapacityADRT 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.)  | GPCons NeuroCons Pall MedCons Resp/Home Vent TeamOther (specify) |

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 Information about the clinical picture in the day before assisted ventilation was withdrawn**

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|  | How many hours a day was ventilation in use (tick one)? | Overnight only<16 hours/day16–22 hours/day>22 hours/dayN/A |
|  | How long could the patient manage without assisted ventilation support? (Tick one.) | Cannot manage at allA few minutes Up to an hourA few hours |
|  | How did the patient communicate in their last days? (Tick one.) | SpeechEye movementsWriting/keyboardThey could notOther (specify) |
|  | What was the patient’s level of independence and function? (Tick one.) | Able to walkMobile with use of wheelchairBed- or chair-bound |
|  | Could the patient use their hands for any tasks? (Tick one.) | YesNo |
|  | What was the level of consciousness in the last days before withdrawal was commenced? (Tick one.) | Fully **A**lertDrowsy, responding to **V**oiceVery drowsy, responding to touch/**P**ain**U**nresponsiveN/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.) |

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| Mode of Ventilation  | Pressure controlPressure supportOther |
| IPAP | cm H2O |
| EPAP | cm H2O |
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|  | 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) | YesNo 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?  | YesNoIf yes, specify details of drugsOpioid: Dose/24hrBenzodiazepine: 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? | YesNoIf 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? | YesNoIf yes, please state in as much detail as possible what you did? |

**Section 3. Information about the withdrawal**

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|  | 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.) | DaysWeeksMonthsYears |
|  | 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 awareNo immediate symptom management was needed before withdrawing assisted ventilationOther (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.) | IVSCIMPOBuccalPer-gastrostomyRectal |
|  | 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.) | MinutesHoursN/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 calmThe patient was drowsy but awakeThe patient was asleep/lightly unconsciousThe patient did not respond to voiceThe patient did not respond to touch/painThe patient had lost corneal reflexOther |
|  | Did you decrease the ventilator settings before completely stopping assisted ventilation? | YesNoIf 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?  | YesNoIf yes, specify and comment: |
|  | Did the patient die with the mask/interface still in place?  | YesNo |
|  | Was the patient conscious after the assisted ventilation was withdrawn? | YesNo  |
|  | How long after the assisted ventilation was withdrawn did the patient live for? (Complete one.) | minutes hoursdays |
|  | Were there any challenges related to family reactions during the withdrawal? | YesNoIf yes, please specify: |
|  | What is your perception of what the experience was like for the family? (Tick one.) | PositiveDifficult; beyond your expectation of normal grievingFrankly traumaticComments on issues/ how it could be improved:  |

**Section 4. After the withdrawal**

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|  | 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? | YesNoIf yes, please specify: |
|  | What was the experience like for you? | PositiveNeutralDifficultFrankly traumaticPlease 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?  | YesNoIf yes, please specify: |
|  | How has this affected your confidence in this area of care? (Tick as applicable.) | My confidence has increasedMy confidence is unchangedMy confidence has reducedI would prefer not to do it again |
|  | Where there any issues that arose in the team debrief? | YesNoN/A no team debriefIf 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

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