The Newcastle upon Tyne Hospitals NHS Foundation Trust

Promoting a Palliative Approach:

Withdrawal of Mechanical Ventilation at Patient Request

Alison Armstrong
Nurse Consultant
North East Assisted Ventilation Service
Alison.armstrong1@nhs.net
@AlisonArmstron

Aims and Objectives

Legal stance

Guidance

Case report

Learning points


EXPERIENCE
EXPERIENCE
EXPERIENCE
EXPERIENCE


We are all in agreement then.

The most challenging decisions in this area are generally about withdrawing or not starting a treatment when it has the potential to prolong the patient's life. This may involve treatments such as… mechanical ventilation.

(GMC. *Treatment and care towards the end of life: good practice in decision making*, 2010)

Withholding and withdrawing treatment

Primary aim of starting a treatment is to provide a health benefit to the patient

The same justification applies to continuing a treatment already started

Psychologically may be easier to withhold a treatment than to withdraw it……

The often short time between withdrawal of ventilation and death feels uncomfortable and causative

In withdrawal of mechanical ventilation, the reason death occurs is because of the underlying disease

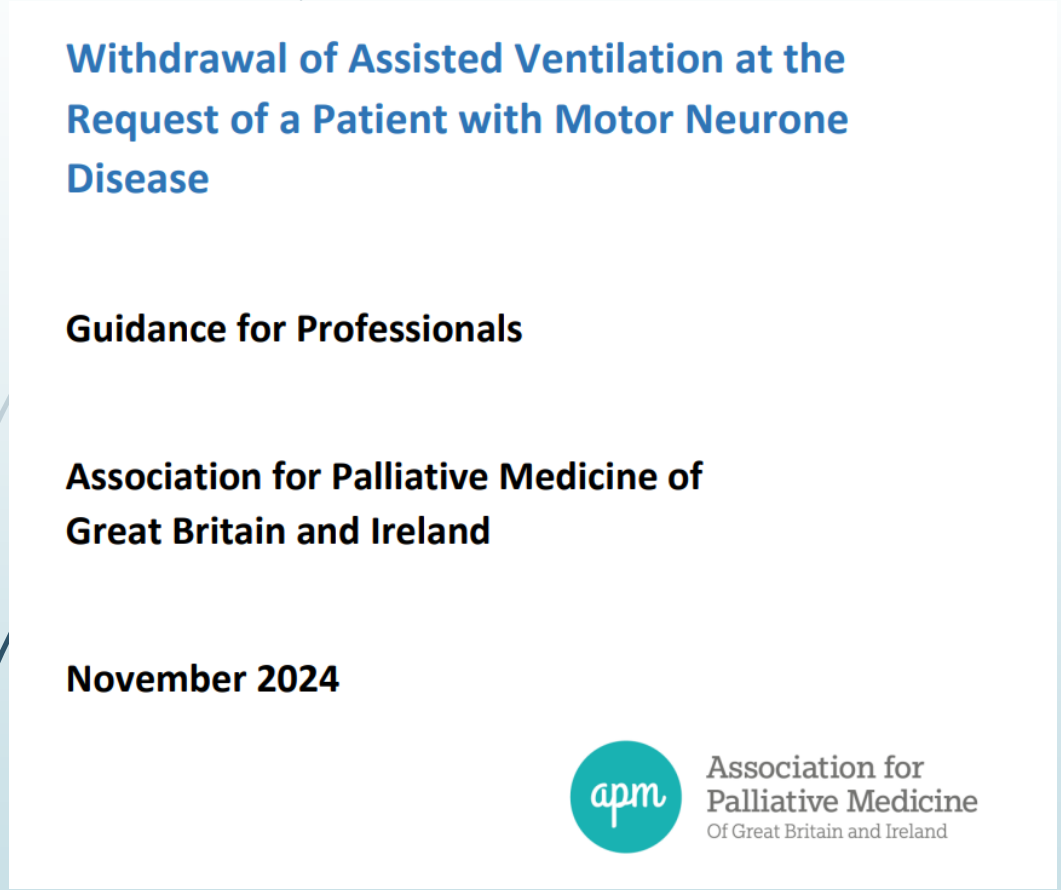
When the patient asks for treatment withdrawal……

“The law requires that an adult patient who is mentally and physically capable of exercising choice must consent if medical treatment of him is to be lawful...

….treating him without his consent, or despite a refusal of consent, will constitute the civil wrong of trespass to the person and may constitute a crime.”

Lord Donaldson MR (1993)

Guidance



The aim of the Guidance is to improve the care of patients and families, and to support health care professionals.

The guidance is aimed towards patients with MND but the principles are transferrable.

Guidance-Final-November-2024.pdf

Standard 1

A patient should be made aware that assisted ventilation is a form of treatment and they can choose to stop it at any time.

They should be in no doubt that this is legal and that healthcare teams will support them.

Inform patients that they can choose to stop the treatment at any time, that it is entirely their right and legal and that their healthcare team will manage their symptoms in a different way.

Promote the concept of advance care planning, and discussion of wishes and values with patients who use assisted ventilation, especially those who have lost one modality of communication.

Standard 2

Senior clinicians should validate the patient's decision and lead the withdrawal.

Affirm the decision by assessing the patient's capacity or validity and applicability of an advance decision to refuse treatment (ADRT) and that this is a settled view; allowing a period of time for discussion and reflection between the initial conversation and the patient's final decision.

Standard 3
Withdrawal should be undertaken within a reasonable timeframe after a validated request

Discuss with the **patient and family** when, where and how withdrawal will happen, including the potential for living for some hours without the ventilator and occasionally longer.

Discuss with the **professionals** when, where and how withdrawal will happen; identify key people and their roles.

Ensure all **members of the team** understand the ethical principles and the legal position.

Coordination is key!

Standard 4
Symptoms of breathlessness and distress should be anticipated and effectively managed

Make a plan for symptom management.

Does the patient require sedation before assisted ventilation withdrawal (anticipatory prescribing)?

What drugs, doses, route?
Who will prescribe and administer?
Who will manage the ventilator and how will settings be adjusted and mask/tubing removed?

For those who are ventilator dependent, assess effectiveness of symptom management by reducing or stopping assisted ventilation for a few minutes before full removal.

Continue to titrate opioids and benzodiazepines to manage symptoms.

Standard 5

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

Consider the needs of family and professionals after death.

Plan who will provide support to family members.

Debrief for professionals/significant event analysis.

Submit data set and share key learning.

Anticipatory prescribing

- Prescribing medicines in anticipation can avoid a lapse in symptom control, which could otherwise cause distress for the individual and those close to them.
- The drugs and dosages prescribed must be appropriate to the individualised anticipated needs.
  - How quickly they may become breathless
  - What medication is already in use
  - Route of administration

- APM guidance: the degree of sedation required (for MV dependent) is that which:
  - Achieves a reduced conscious level with no response to voice or painful stimulus
  - On the 'test' reduction of assisted ventilation, no symptoms are precipitated

Association for Palliative Medicine
Of Great Britain and Ireland

Case study

- Steve
- 55 years old
- Motor Neurone Disease

November 2012

Diagnosed MND

January 2015

- Lower limb weakness; right upper limb weakness
- Morning headache
- Orthopnoea
- Reduced PFTs
- Well preserved bulbar function
- Referral for NIV

January 2015	• Commenced NIV – expectations discussed
March / April 2015	• Further respiratory deterioration and NIV use increased
May 2015	• Ventilation dependency almost 24/7
June 2015	• Request to discuss treatment withdrawal and EoL management

20.07.15 – Meeting at home

- Still able to manage 15 – 30 mins ventilator free breathing
- Steve very clear about what level of disability he was prepared to tolerate
- process of NIV withdrawal discussed
- Capacity assessed
- ADRT discussed and recorded
- Personnel to be involved agreed
- All parties aware of who to be contacted when approporiate

11.08.15

Family made team aware that Steve felt his QoL had deteriorated and withdrawal of NIV requested

11.08.15

- Immediate planning:
  - Arrangements made to visit the following evening
  - S/C access secured
  - Stat dose (2.5mg) of sedation and opiate given that evening with little effect

12.08.15

- Driver installed that morning – each at 10mg / 24 hour.
- Further stat dose (5mg Morphine and 5mg Midazolam) given
- Steve comfortable throughout the day, but did require further stat dose of 15mg Midazolam/ 5mg Morphine around 16:00 and 16:30
- Now very settled
- All family members present and aware of plan

- Spoke with family about the events that may follow; expectations prepared
- Initially reduced ‘back-up’ respiratory rate from 12 to 8bpm
- Further stat dose 15mg Midazolam given 17:45
- Over the 45 minutes that followed, inspiratory pressure reduced from 18, to 12, then to 8cmH2O

17:30

- Although some spontaneous breathing, no arousal or distress evident, therefore ventilator switched off

18:15

- Mask initially left in place in case treatment had to be recommenced and sedation reviewed
- Mask then removed

18:20

- When we left, Steve continued to breath spontaneously, but appeared settled throughout

18:30

Steve continued to make spontaneous respiratory effort but remained settled, until he died just after 2am on Friday 14th August

Reflection

What went well?

- Steve decided, and therefore had full control over, when his treatment should be discontinued. “MND is not taking any more of me”
- Continued dialogue between Steve, his family and health care team to ensure wishes were known and revisited
- His death was peaceful and dignified, with his family around him
- He and his family were included in all discussions and preparations
- Communication and co-ordination between those involved
- “Dream Team!”

What have we learnt?

- The practicalities around these arrangements left a feeling within the health care team that this situation was engineered
  - Family saw this as necessary and positive
- Time between decision being made and commencement of plan is critical
- Separate room for drug preparation if possible
- Disable all ventilator (and humidifier) alarms in advance
- Leave the mask on for a moment after ventilation has been discontinued as a ‘test’
- Removing NIV will not always result in immediate death – all need to be prepared for this
- Separate roles between palliative care team and home ventilation team – but collaboration is key!

The Effect of a training session on Health Care Professionals' confidence in withdrawal of mechanical ventilation in Motor Neurone Disease

64 delegates rated their confidence on a scale of 0-10 in the management of MV withdrawal from an ethical, legal and practical point of view before and after the training session.

	Ethical Pre-training	Ethical Post-training	Legal Pre-training	Legal Post-training	Practical Pre-training	Practical Post-training
Mean (/10)	3.7	7.8	3.5	8.1	2.9	7.3
P value		0.001		0.001		0.001

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Thank you!
Questions?

Alison Armstrong
Nurse Consultant
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Alison.armstrong1@nhs.net
@AlisonArmstron