Withdrawal of Ventilation in MND

Dr Emily Sills Consultant in Palliative Medicine
&
Sarah Fidler Nurse Consultant
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Objectives

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- NIV in MND
- Legal aspects
- Ethical aspects
- Practical considerations

Assisted ventilation in MND

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- Respiratory muscle function will worsen & if untreated respiratory complications eventually can cause death
- Assisted ventilation is a **MEDICAL TREATMENT** that can improve quality of life, symptoms and survival in selected patients and NICE supports its use [1,2,3]
- Assisted ventilation- NIV and TV

Stopping ventilation

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- For the majority of such patients, NIV does not complicate the dying process; if its benefit has been lost, then those using NIV only at night may simply choose not to put it back on.
- For others, NIV may continue to provide benefit throughout the dying process
- It is a patient decision as to whether they chose to have assisted ventilation and they have a legal right to discontinue this treatment
- Discontinuation of ventilation appears to generate more concern than withdrawing other forms of life prolonging treatments

Challenges in NIV withdrawal

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- Professionals may fear that they will not be able to provide adequate symptom management and that the patient will have a distressing death. They may also be concerned that withdrawal may be seen as actively ending the person's life.
- There may be conflicts within teams as team members have their own ethical positions

Challenges from 2013 scoping study

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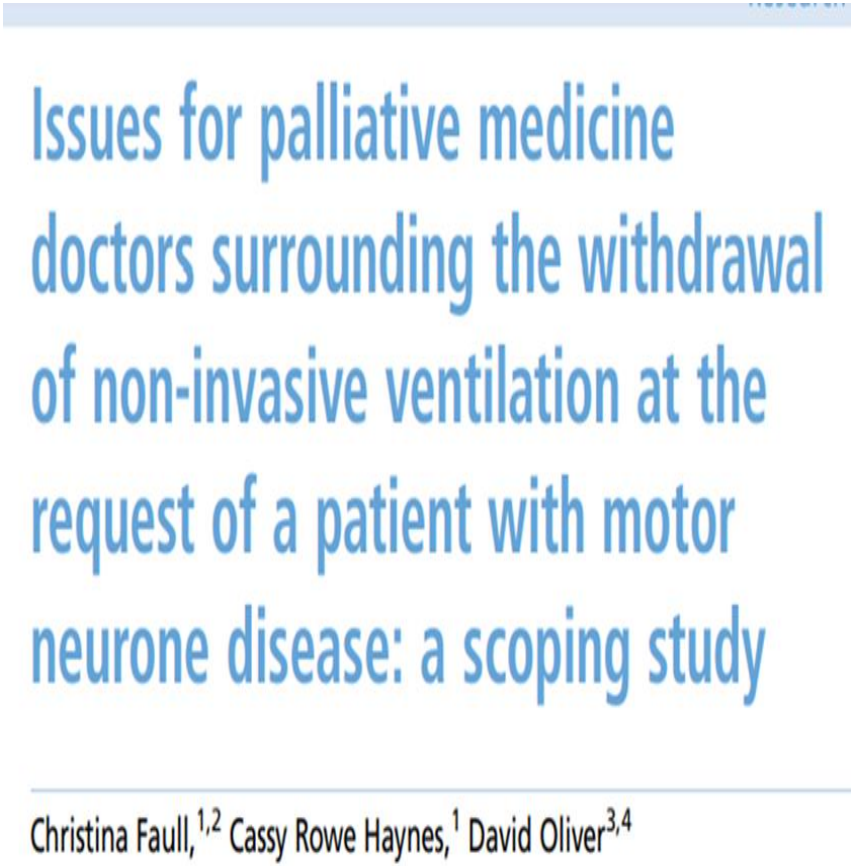
- Care teams and families found both the decision making and the withdrawal itself very difficult
- Withdrawing ventilation at the request of patient with MND was often an emotionally intense experience which left a profound mark, particularly for those leading the withdrawal
- There was a wide variation in practice
- Both family and professionals may feel very isolated
- This can have an impact on future practice


Issues for palliative medicine doctors surrounding the withdrawal of non-invasive ventilation at the request of a patient with motor neurone disease: a scoping study

Christina Faull,[1,2] Cassy Rowe Haynes,[1] David Oliver[3,4]

OPEN ACCESS

Withdrawal of ventilation at the patient's request in MND: a retrospective exploration of the ethical and legal issues that have arisen for doctors in the UK

Kay Phelps,[1] Emma Regen,[1] David Oliver,[2,3] Chris McDermott,[4] Christina Faull[5,6]

► Additional material is published online only. To view please visit the journal online (http://dx.doi.org/10.1136/bmjspcare-2014-000826).

ABSTRACT

Background Ventilatory support has benefits including prolonging survival for respiratory failure in motor neurone disease (MND). At some point some patients may wish to stop the

the ethical challenges is needed as well as education and support for professionals.

BACKGROUND

Motor neurone disease (MND) is a pro-

Table 1 Legal and ethical themes emerging from interviews with doctors

Main theme	Subthemes
Theoretical knowledge of ethics and the law	Is withdrawal ethical and legal Is it unethical or illegal not to withdraw Under what circumstances is it legal and ethical to withdraw What if patient is not close to death
Ethical and legal practice	Experience and knowledge Discussions of ethics and the law with colleagues, patients and families, including disagreements. Palliation of symptoms—what is legal External scrutiny, the need to document practice and work in teams for legal security Protecting the family ethically, morally and legally
Does withdrawal feel ethical and moral	Felt right Felt uncomfortable or wrong Fear of misinterpretation as assisted death Ethical and moral burden
Ethical and legal recommendations	Need for legal and ethical guidance Need for professional education

Legal aspects

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- In UK law a refusal of a medical treatment by a patient who has capacity for that decision, must be respected and complied with.
- To continue to give treatment without consent constitutes an offence.
- A patient with capacity may either refuse ventilation or ask that it be withdrawn, either at the time or by an advance decision to refuse treatment (ADRT).

Patient who lacks capacity

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- Ideally patients who become ventilator dependent would have an ADRT
- In the absence of an ADRT but where there is a LPA (health and welfare) requesting withdrawal, the MDT must agree that it is in the 'best interest' of the patient (Mental Capacity Act 2005)
- In the absence of ADRT and LPA, withdrawal decisions must be based on patient's best medical interest this may require a court appointed deputy.

Ethical considerations

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- Autonomy
- Beneficence
- Non-maleficence
- Justice

Advance care planning

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- A statement of wishes and preferences is a written, recorded or narrative document that states the patient's values in both clinical and non-clinical circumstances. While it is not legally binding it can be used as an account of the person's wishes when a person loses capacity and best interests need to be established.

- The Mental Capacity Act (MCA) for England and Wales (2005) underpins advance care planning and sets the legal context for such conversations and patient directions.

ACP (cont)

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- Patients make settled decisions about the withdrawal of assisted ventilation over time and many factors support and influence this. Key to such decision-making is the availability of timely and accurate information for the patient. This requires the patient has the necessary facts, the opportunity to ask questions and a skilled professional to enquire and prompt thinking about future potential scenarios.

- Whilst most patients want to continue their non-invasive assisted ventilation until they die, professionals need to proactively and sensitively enquire about their thinking about the tolerability of their situation now and in the future.

Is this suicide?

- Action of killing oneself intentionally
- Ventilation has prevented death from MND and prolonged life
- Stopping ventilation merely re-establishes the chain of causality- it isn't an action to cause death
- Patient is NOT committing suicide the MND is causing their death

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Is this Euthanasia?

- Euthanasia is the painless killing of a patient suffering an incurable & painful disease or in a irreversible coma- intent is to cause death

In a ventilator dependent patient:

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- Withdrawal of ventilation may lead to:
  - Rapidly and severely increased breathlessness
  - Death in short period of time

- "Relieving a patient of discomfort and distress is a fundamental medical responsibility and parallels the use of both local and general anaesthesia or sedation prior to invasive interventions." APM

Tap above to play video

Julie's choice to stop NIV

"After being with you though everything, I get it and I fully support you"

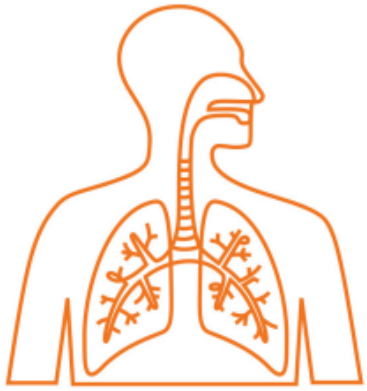
- Russ, Julie's son

This is a poignant video that some people may find upsetting.

Julie and her son Russ tell us about their carefully considered decision for Julie to withdraw from NIV. This video was filmed a few weeks before Julie died.

Julie lived with MND/ALS for eight years. She talks here about how she felt her symptoms and quality of life had become unbearable for her. As ventilation is a treatment, people can refuse to continue with it.

mnda
motor neurone disease
association



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Withdrawal of ventilation with MND

Information for people with or affected by motor neurone disease

MND can affect your breathing muscles as the disease progresses and you may be referred to a respiratory team (breathing specialists). They will explain the support available and you may choose to accept help from a machine with your breathing. This is known as ventilation. Over time, you are likely to become reliant on ventilation, so you need to be fully informed about your choices. Ventilation support can improve quality of life and may prolong survival, but it cannot reverse the disease or stop it from progressing.

Lancaster Court, 8 Barnes Wallis Road, Fareham, PO15 5TU

WITHDRAWAL OF VENTILATORY SUPPORT AT THE REQUEST OF A PATIENT

Withdrawal of Assisted Ventilation at the Request of a patient with Motor Neurone Disease

The APM have published Guidance for professionals in this complex area of care. Many of you will have contributed either to the research or the consultation about this work which was lead by Christina Faull.

The Guidance was developed by a multi professional and inter speciality group and is endorsed by the RCP, Hospice UK, the MND Association and the GMC have affirmed it is consistent with standards of good practice. The Guidance has been reviewed by the medico-legal secretary of the Coroners' Society of England and Wales for compatibility with coronial law and principles.

The Guidance calls for ongoing evaluation of a core dataset and the outcomes from 46 patients were published in 2020 Mechanical ventilation withdrawal in motor neuron disease: an evaluation of practice | BMJ Supportive & Palliative Care

Standards recommended in APM guidelines

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- **Standard 1:**

Patients should be made aware that they have the right to ask to stop ventilation. They should be in no doubt that this is legal and that healthcare teams will support them

- **Standard 2:**

A senior clinician should lead the planning and coordination of the withdrawal

- **Standard 3:**

Withdrawal should be undertaken within a few days of an affirmed request -

Standards recommended in APM guidelines (cont)

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- **Standard 4:**

Symptoms of breathlessness and distress should be anticipated and effectively managed

- **Standard 5:**

Family members should have appropriate support and opportunities to discuss the events with the professionals involved

Practical considerations

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- Multi-disciplinary team approach (seek guidance from APM)
- Discussion with patient and family
  - Acknowledging difficulty and impact of decision, concerns and expectations explored
  - Reassurance around the ethical and legal position, the distinction between assisted death and stopping life-prolonging treatment
- Professionals including paid carers
  - Discussion with MDT involved in person's care
  - Do not underestimate time needed
- Detailed plan
- Symptom management

Detailed plan

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- Medication- access to
- Who will give it
- How the ventilator will be managed
- Who will be altering the ventilator/ removing the mask
- Ensuring support is available for family
- Consider shift changes

Post withdrawal

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- Family support
- Staff support- debrief session
- An opportunity for families to come back later and ask questions

https://portal.e-lfh.org.uk/LearningContent/Launch/722481

Non-invasive ventilation in motor neurone disease

Description

Non-invasive ventilation (NIV) is an intervention which can improve both quality of life and survival for patients with motor neurone disease (MND). This session outlines the evidence base and practicalities of this important treatment option for patients.

The session was last reviewed by Jon Palmer and Rich Kitchen in March 2022.

Authors Christina Faull, Juliet Colt, Jonathan Palmer , David Oliver

Duration 30 min

Audience This session is aimed at specialists in palliative care including nurses, doctors and therapists. It may also be useful to GPs and community nurses supporting patients with MND who are using NIV.

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Questions and discussion

References

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1. Bourke SC, Tomlinson M, Williams TL, et al. Effects of non-invasive ventilation on survival and quality of life in patients with amyotrophic lateral sclerosis: a randomised controlled trial. Lancet Neurol 2006;5:140–7.
2. Piepers S, van den Berg JP, Kalmijn S, et al. Effect of non-invasive ventilation on survival, quality of life, respiratory function and cognition: a review of the literature. Amyotroph Lateral Scler 2006;7:195–200.
3. National Institute for Health Care Excellence. Clinical Guideline 105: Motor Neurone Disease; the use of non-invasive ventilation in the management of motor neurone disease. NICE, 2010.

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- NICE guideline (NG42) Motor neurone disease: assessment and management This guideline sets out recommendations to professionals for the treatment and care of MND, including planning for end of life. See: www.nice.org.uk/guidance/ng42
- Withdrawal of Assisted Ventilation at the request of a Patient with Motor Neurone Disease. Guidance for professionals: published by the Association for Palliative Medicine of Great Britain and Ireland. https://apmonline.org/apm-professional-guidelines-2
- MyBreathing – this website has videos on experiences with ventilation, including decision making about end of life. See: https://mybreathing.mymnd.org.uk/later-decisions

References (cont)

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- e-learning for healthcare website:

https://portal.e-lfh.org.uk/LearningContent/Launch/722481