

# Introduction to Withdrawal of Assisted Ventilation in MND

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# Introduction

- Summary of guidance from Association of Palliative Medicine
- Legal considerations
- Reflections on my own experience

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

## Guidance for Professionals

### Association for Palliative Medicine of Great Britain and Ireland

2015



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#### Endorsements

The Education and Standards Directorate at the GMC have advised us that this guidance is consistent with the standards of good practice set out in their guidance on *Treatment and Care towards the End of Life*.

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.

# Principles underpinning the guidance

- The decision is an **individual** for every patient and their family
- For a patient dying from MND, it is their **legal right** to refuse assisted ventilation and the **duty of professionals** to manage this.
- **Communication** with patient, family, between professionals fundamental in **achieving sensitive, safe, effective** care.
- **Teamwork** is key to achieving best outcomes for the patient and requires **senior clinical leadership**.
- The need for **psychological** support for the **patient, family and professionals** should be anticipated and planned for.
- Although there are general principles of symptom management, this needs to be **individualised** for each patient.
- Need for **ongoing evaluation of methods and outcomes**.

# Standard 1: When commencing ventilation and throughout care

- 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.

## Standard 2: Withdrawal of assisted ventilation

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

# Standard 3: Withdrawal of assisted ventilation

- Withdrawal should be undertaken within a reasonable timeframe after a validated request.

## Standard 4: Withdrawal of assisted ventilation

- Symptoms of breathlessness and distress should be anticipated and effectively managed.



## Standard 5: after death

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

# Legal considerations

- UK law: refusal of a medical treatment by a patient who has capacity for that decision, must be respected and complied with.
- Assisted ventilation is a medical treatment.
- Patient's must have capacity when making a decision OR
- In a patient lacking capacity, decisions can be made:
  - Using an ADRT
  - In consultation with a Lasting Power of Attorney for Health and Welfare
  - In the patient's best interests
- Whilst timing of death is influenced by the withdrawal of ventilation, the cause of death is the advanced neurological condition.
- Withdrawal of life sustaining treatment allows a natural death

My own  
experience –  
putting theory  
into practice



# References

- Withdrawal of Assisted Ventilation at the Request of a Patient with Motor Neurone Disease: Guidance for Professionals (2015). Association for Palliative Medicine of Great Britain & Ireland.
- General Medical Council Professional Standards: Treatment and care towards the end of life: good practice in decision making (2010).
- Mental Capacity Act 2005
- 8C: Withdrawal of ventilation with MND. Motor Neurone Disease Association:  
<https://www.mndassociation.org/media/119>