Withdrawal of assisted ventilation at the request of a patient with MND
Recommendations from the research study

This paper draws together the recommendations arising from research funded by LOROS and the Motor Neurone disease Association. It is written primarily for a professional audience. These recommendations contain frank unedited views of the research participants and focus on specific details around issues related to withdrawal of ventilation at the request of a patient with MND.

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1. Discussions About Withdrawing Ventilation

Discussions about the possibility of stopping or withdrawing ventilation should be held as early as possible so that patients and relatives are aware of their options and how their choice would be supported.

When a decision to withdraw treatment has been made health care professionals should explain the process of what will actually happen as clearly and comprehensively as possible. Where uncertainty exists (notably with regard to symptom control and how long the withdrawal and death will take) they should communicate and discuss this with patients and relatives beforehand.

Discussions about the possibility of withdrawing ventilation need to take place in a timely manner so that patients’ wishes can be incorporated into advance care planning and decisions while they still have capacity.

Some relatives would appreciate more candid conversations with doctors and health care professionals at an earlier stage regarding the implications of ventilation for quality of life, the issue of dependency and its consequences at the end of life and for how a person will die.

Timely discussion with patients and families concerning their understanding of their right to stop ventilation and the way this would be supported could spare distressing conversations about suicide and assisted suicide.
Some relatives would appreciate more timely and detailed information about the option to withdraw ventilation and what this actually entails in practise with regard to the mechanics of withdrawal, symptom control and timing. Whilst perhaps not appropriate for all, such information should be available and accessible for those who desire it at a time of their choosing.

In order to minimise additional stress relating to the actual process of withdrawal, patients and relatives should be given detailed information about the mechanics of withdrawal including symptom control, the use of medication and the timing of withdrawal and death. Where there is uncertainty about these elements this should be acknowledged and discussed.

Discussions about withdrawing ventilation should involve patients, family members and health care professionals with the aim of fostering consensus of support for the patient’s decision.

Communication between all parties should be open and honest. Relatives should feel free to raise any concerns or questions and to be able to express their own views about the withdrawal.

A patient’s wishes should be are known to all professionals involved. Discussions should be open and documented. This is reassuring to health care professionals and family alike.

Any concerns or doubts (family or professional) about patients’ wishes should be identified early and discussed fully. Court cases to determine patients’ wishes should be an absolute last resort.

In order to prepare both practically and emotionally, some relatives may wish to speak with, or access the experiences of others who have gone through the process.

2. Ethical Issues

Open ethical discussions of these situations and written guidance on the ethics of withdrawal of ventilation in MND would alleviate many doctors’ and other health care professional fears.

Relatives and professionals should not be left with doubts as to whether they were involved in something unethical or illegal.
Though the legality and ethics of withdrawal of treatment at the patient’s request are clear, applying this to withdrawing ventilation in a patient who will then die from neuro-muscular respiratory failure can in practice be challenging for many doctors and health care professionals.

Discussions and written guidance regarding the ethics and legality of withdrawing ventilation in MND should be widely disseminated and accessible to any doctor or health care professional who is involved in this area of care. Specific issues that need clarity are the circumstances under which it is legal and ethical to withdraw treatment; symptom control; and the distinction between withdrawal and assisted suicide.

Medical defence organisations need to provide accurate, clear and consistent advice to doctors seeking information and reassurance regarding the withdrawal of ventilation at the request of a patient with MND.

Health care professionals should be aware that patients and family members may have concerns about the ethics and legality but may not voice them.

Discussions about the withdrawal of ventilation need to clearly state the ethical rationale [In short: That this is a treatment that the patient is telling us to stop. They are allowed to do that and we are obliged to comply with that wish. To stop ventilation requires us to manage their symptoms in a different way]. This may need to be heard on many occasions by both family and professionals as there is for many people a personal, internal tension between ‘rationale’ and ‘emotional belief’ (head vs heart) in this situation.

It is the job of the professionals, most especially doctors, to support patients and their relatives through difficult decisions such as withdrawing from treatment without imposing their own personal and religious beliefs. Clinicians should advise of options and provide a medical ethical legal opinion, not a personal view.

Though the families’ views and distress should be considered, the rights of the patient are paramount.

A request for withdrawal should be discussed within the clinical team where ethical and legal concerns can be identified and discussed. It is wise to involve someone who has knowledge and experience of the issues surrounding withdrawal of treatment and end of life care.

More than one clinician should be involved.
3. Advance Decisions to Refuse Treatment

Patients with MND, especially those who choose assisted ventilation, should be informed of their right, and given supported opportunity, to draw up an Advance Decision to Refuse Treatment (ADRT) as part of Advance Care Planning discussions.

They should be as detailed and specific as possible with the patient’s wishes recorded on appropriate and robust documentation. Templates, such as the one provided by the MNDA may assist patients and relatives in formulating their wishes.

Careful attention should be paid to both the wording and the inclusion of any requirement for review which may later affect their validity.

Noting that the ADRT decisions have been discussed and affirmed or altered will aid their later application and will ensure that any inconsistencies or errors may be quickly identified and addressed.

Health care professionals may need more training to understand the appropriate use and purpose of ADRTs. Specifically, that such documents are not required in order to enact decisions when patients are able to express their wishes to refuse certain treatments.

It may be helpful for patients and doctors to regard an ADRT as part of the decision making process rather than the ‘be all and end all’. Despite careful wording and consideration, there will be occasions where doctors will be required to make best interest decisions about if and when ventilation be withdrawn using the ADRT as a guide.

4. Capacity

If unsure about a patient’s mental capacity to make decisions about withdrawing treatment get a second opinion.

It should be clear that the wish to withdraw treatment is consistently sustained.

5. Communication Challenges
Every effort should be made to have discussions about treatment and end of life wishes with the patient and their family when one modality of communication (written or oral) has been lost.

It should be anticipated that communication will become difficult and may change very quickly.

Reliance on family to interpret communication is not ideal as they may have different views to the patient. Try and ascertain patient’s views from themselves where possible.

Communication challenges and fatigability mean that sufficient time must be allowed for such discussions.

Relatives who had had the opportunity to hear and discuss wishes with the patient, especially in the presence of a health professional, were relieved and reassured that they were fulfilling a patient’s wishes and not having to make decisions themselves.

Training should be available for health care professionals in how to have difficult discussions and also in communication techniques with people who have lost or who are losing speech.

6. Withdrawal & Symptom Control

Things for HCP’s to consider in advance

- Timing
  - When a patient expresses that they would like to withdraw from ventilation, delays can be distressing for them and their family
  - The family will need support throughout the withdrawal process which may be lengthy.
  - When: morning, not near weekend
- Consider who will be involved and ensure all professionals know their roles. At least two health care professionals are needed for:
  - Symptom management
  - Ventilator/interface withdrawal
  - Family support
- Consider the method of withdrawal and involve a ventilation expert where possible. Get detailed practical advice on the settings and alarms of the ventilator
- Consider and discuss symptom management and involve a specialist (e.g. palliative care consultant). Discuss options should the patient becomes distressed (re- ventilate or not is a key decision).
- Discuss the practicalities with a professional who has undertaken this before
Information to share with patients and relatives in advance

- **Timing**
  - It may take time for the withdrawal to be set up as key health care professionals may be required to be present and may need to block out half a day in their diaries.
  - The time before the patient dies may be quick (minutes) but is often longer (hours) depending on factors such as:
    - The type of ventilation (NIV/IV)
    - The dependence of the patient on the ventilation
    - The health of the patient
    - The method of withdrawal (weaning may extend the process)
  - Family will need support throughout the withdrawal process which may be lengthy
- **Consider and discuss who you think should be involved and what they will do:**
  - Professionals
  - Family and friends

Before the withdrawal

- **The plan for the withdrawal and symptom management should be discussed and agreed by the immediate health care team, to address any concerns or issues.**

Detailed information for relatives and patients (not all may want all of this)

- **Method of withdrawal**
- **Symptom control**
  - Address relatives fears of patient distress
  - Discuss what will happen should the patient become distressed
    - Increased medication or replacing ventilation
- **Physiological changes which may occur in the patient during withdrawal**
- **Who will do what**
  - Ventilator
  - Symptom control
  - Family support

Address any concerns or issues.
Give space to say goodbyes.

During the withdrawal

- **Professionals should be present at all times:**
  - To give symptom control (ideally a specialist clinician)
  - To wean or switch off ventilator (consider involving the ventilator specialist)
To support the family emotionally (ideally someone the family know well)
  o Relatives should not be left alone to withdrawal ventilation or deal with a distressed patient but should be supported throughout

Method of withdrawal
- Method of withdrawal should be discussed with the ventilation specialist
- This should be discussed beforehand within the health care team and thoroughly explained to the patient and relatives.
- Methods of weaning and switch off and the symptom control associated with each should be discussed and a decision made in conjunction with the patient’s wishes and the views of relatives where they have been the main carer.
- Carers views on method of withdrawal should be taken into consideration.
- Though relatives may want to have some part in the withdrawal, such as removal of the mask, this should only be at their request. A professional should be responsible for the ventilator withdrawal which ever method is used.
- Relatives are often ‘experts’ on ventilator use, but that does not mean they should be responsible for withdrawal.
- If weaning is used, then this should be carried out over a planned, short period with adequate symptom control to prevent any distress.
- Once ventilation has been removed every effort should be made to control symptoms with means other than ventilation. Replacing ventilation is not usually what the patient wants, though this should be discussed beforehand.

Method of symptom control during withdrawal
- Relatives’ main concern for their loved one is that they experience no distress. Unfortunately half of the relatives in our study felt that their loved ones had experienced distress during the withdrawal or in the days leading up to it. It was the view of most relatives that patients should be sedated prior to withdrawal and protected from distressing symptoms of breathlessness and anxiety.
- The primary aim of symptom control should be to prevent patient distress rather than have to respond to it. It is very harrowing for a relative to be alone with a distressed patient with no one present to administer symptom control.
- Whether symptoms were controlled or not depended on whether a specialist clinician was involved; whether a clinician remained with the patient; the method of withdrawal.

Medication, dosage and administration for withdrawal
- Someone who can administer adequate symptom control to the patient to prevent distress should stay with the patient from withdrawal until death.
Who should be Involved in Withdrawal

- In five cases discussed by relatives there was no clinician present at the time of final withdrawal and death, and in two of these there were no health care professionals present at all. In all of these cases the relatives felt that the patient had experienced some distress either in the lead up to the withdrawal, during weaning or once ventilation had been removed. We would recommend that a clinician be present during withdrawal through to death to manage symptoms and ensure patients do not experience distress.

- Relatives were very aware of the lack of experience of the health care professionals involved with their loved ones at dealing with ventilators, MND and withdrawal. This led to lack of confidence and anxiety. We would advise that health care professionals involved at the very least talk to someone who has carried out a withdrawal, and at best involve someone with experience.

- Only four of our small sample had a ventilation expert present during the withdrawal. Those that did found this to be useful. The majority of relatives in our study felt that the health care professionals providing care for their loved one had little knowledge and experience of ventilators and usually left this aspect of care to the relative. Where patients were receiving invasive ventilation most care staff seemed to have received some training in ventilator care. We would recommend that a ventilation expert be present during the withdrawal to deal with the ventilator, or if not possible ventilator advice should be sought prior to the event.

- It is vitally important to establish beforehand who will be responsible for the ventilator, whether weaning or removing. It should be established in advance how alarms can be silenced and who will deal with all aspects of ventilation removal. Many of the relatives in our study were involved in removing ventilation, not all through prior discussion and choice.

- In most (11) of our cases there was a palliative care consultant involved in the withdrawal for the purpose of symptom control. All cases of invasive ventilation withdrawal included a specialist. There was a positive correlation between the presence of a palliative care consultant or an anaesthetist and a peaceful death; we would therefore recommend that a specialist be present for symptom control.

Setting for Withdrawal

The majority of relatives in our study experienced withdrawal at home. There appeared to be no difference in terms of setting as to whether patients experienced distress or not.
Our study indicates that it is just as possible to have specialists present and to experience a peaceful, symptom free withdrawal at home as it is in a hospice or hospital.

7. Support for family

The withdrawal of ventilation and the loss of a loved one is clearly a very emotional experience for relatives – one where a range of conflicting feelings may emerge and be held in tension. Relatives can feel the imperative to be strong advocates for the patient’s wishes. This can be a substantial strain and relatives may need to be supported through this process by having access to appropriate emotional support mechanisms of their own choosing (both formal and informal).

Receiving support from people with direct experience/understanding of MND appears to have been particularly beneficial to relatives/carers and should be encouraged (e.g. MNDA visitors or being put in contact with other carers of people with MND on a one-to-one basis).

Children affected by MND both during the illness or after a parent’s death may benefit from contact with other children in similar situations (specifically relating to MND). Such contact may help to counter feelings of loneliness and isolation experienced by young families.

With regard to the withdrawal of ventilation specifically, some relatives would appreciate more support for the decision making process. Being able to speak to someone with specialist knowledge about withdrawal of ventilation or to be able to speak to/access the accounts of relatives who have been through the process would help relatives on both the practical and emotional levels and reduce feelings of loneliness and isolation.

Relatives should be able to air and discuss their views and emotions regarding the decision to withdraw ventilation even where these are contrary to those of patients.

Relatives felt that ventilation and the focus on withdrawal from ventilation could prevent MND patients from being treated as a palliative, and thus have a negative impact on their end of life care. MND is a palliative condition and should be treated as such. Withdrawal from ventilation should be approached as other end of life care would be.

A patient wishing to withdraw from ventilation has made a difficult and distressing decision. Patients and their families need their medical team to be knowledgeable about the ethics of withdrawal so that they appear confident and competent and do not add to the family’s already considerable emotional distress. Disagreement within the team causes delays and will directly affect the patients care in terms of place, involvement of staff, method of withdrawal and symptom control. Thus the health
care team should know the legal and ethical theory of the patients right to withdrawal from treatment and present a confident and competent face to the patient and their family. Expertise and experience should be sought in advance to prevent unnecessary delays.

Some relatives had experienced negative reactions from friends and family about the morality, ethics and legality of withdrawal from ventilation, and many did not discuss the withdrawal for fear of being judged as helping their loved one die. The moral and ethical distinction between assisted death and stopping life prolonging treatment is important to relatives.

Many of the relatives in our study (11/16) were physically involved in the withdrawal of ventilation by removing the mask, or tube, or weaning or switching off the ventilator. Some relatives wanted to be involved but many were shocked at being asked to take part by health care professionals. More than one relative was left alone during the withdrawal.

Relatives should not be placed under additional stress by being expected to play an active role in the withdrawal process unless they specifically request this. Where withdrawals are taking place in the patient’s home, there should be appropriate support from health care professionals to ensure that relatives are not required to take on responsibilities (e.g. turning down the ventilator) beyond their own choices and capabilities.

Relatives should not be left alone during a withdrawal unless this is their wish.

Relatives may need support after the withdrawal and still have questions and issues they need to discuss with the health care professionals involved.

8. Support for professionals

Doctors and other professionals should be able to access practical advice and support as to how to undertake the withdrawal of ventilation in MND from more experienced colleagues.

A national support network of experienced specialists to provide advice on ventilation withdrawal in MND.

The availability of written guidelines would be helpful.
This support is particularly important for professionals carrying out the procedure for the first time.

Withdrawing ventilation at the request of patients with MND can be a very emotional experience for all health care professionals, one which leaves a profound mark. Health care professionals should be able to access appropriate emotional support both during and after their involvement in such cases.