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

November 2015

Christina Faull
Assisted Ventilation in MND

Most deaths in MND are due to respiratory failure.

NIV can both improve quality of life and prolong survival.

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.
Patient and Carer experiences

Over the following couple of years my condition has deteriorated to the point where at the moment obviously I can no longer walk, can no longer weight-bear. I have relatively little use of my arms now. But still I'm able to sort of talk and so on quite happily, provided I have a ventilator. Anything more than that and without a ventilator I run out of breath very quickly. Initially I was given the ventilator just for night use. But that was in what? March 2006. But within a couple of months I was using it most of the time because the breathing was being affected, the chest muscles and so on were being affected by the same condition.

So the ventilator is quite a new thing that you've had. How

But I think really before he got the ventilator he was in a very shabby state, his breathing and the toxicity, and the headaches, and the falling asleep all day long. The ventilator, a sort of bi-pack machine was absolutely astonishing. It reset his whole system. It gave him energy, he didn't have to rest between every process of getting up, you know, shaving and teeth and, you know, which was really laborious. It absolutely restored his system. Only now I suppose, less than a year later everything else has caught up and it's, he's more and more dependent upon it put it that way, so.

I mean we had problems in the first hospital with a ventilator because it was a machine they'd only just acquired. They weren't familiar with how it worked. That was one of the reasons Bill went back to the hospice to get it set properly, the
Withdrawal of Assisted Ventilation

- 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).
Stopping Assisted Ventilation in Dependent Patients

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

Speed of symptom onset related to degree of dependence

Anticipatory symptom management
- Proportionate, effective and defensible

“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
What?
So What?
Now What?
# 130 Palliative Medicine Doctors’ perception of the challenges

Doctors with direct experience n= 76

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Doctors with no direct experience n= 54

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Significant numbers scoring 10 on each category

Faull et al BMJ SPC 2013
Exploring Experiences

Interview study with 67 HCPs and family involved in NIV and/or IV withdrawal at the request of a patient in the past 5 years.

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<td>Family</td>
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<td>Other HCPs</td>
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Phelps et al BMJ SPC 2015
Impact on HCPs

- Emotional intensity
- Longer term emotional impact ‘stayed with me’
- Felt: Different, challenging, contrary to training
- Negative reactions from other health care professionals, lack of support from employers and concerns about reprisals
Our problem came when Steve decided that enough was enough when his swallowing became severely affected and he wanted to die at home.

After much legal wrangling we got our wish and Steve died peacefully in my arms after I had removed his mask.

I have lived with this for over 4 years. I spoke at the West Midlands MND conference but have never heard of other cases. It’s good to know that you are not alone and that others have been faced with the same decision and chosen the same route.
Summary Findings

• 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.
Mentor list held by APM
apm@compleat-online.co.uk

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http://apmonline.org/publications/
1. A patient should be made aware that assisted ventilation is a form of treatment and that 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.

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

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

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

5. After the patient’s death family members should have appropriate support and opportunities to discuss the events with the professionals involved.
Many professionals may not be experienced in withdrawal of ventilation in MND and some may feel overwhelmed or unsure about the laws governing withdrawal. In some cases, they may even refuse to help if they worry it may be confused with assisted dying. If this happens, ask for referral to a specialist palliative care team.
Non-invasive Ventilation in Motor Neurone Disease

End of Life Care  Guidance for Withdrawal of NIV

A clear plan should be made before any withdrawal, it should cover:

- Medication
- Who will give medication
- How the ventilator will be managed
- Who will be altering the ventilator / removing the mask
- Ensuring support is available for family
- Consider shift change-overs as a considerable number of hours of support and care may be required

The plan should also encompass after the withdrawal and cover:

- Ensuring the family are supported
- Staff support (a debriefing session is often very helpful)
- An opportunity for families to come back later to ask questions and talk over what has happened
How to manage symptoms

- Decide the intention: Anticipatory sedation or augmented symptom management
- Decide the route of drug admin
- BZD + morphine
- Titrate to comfort/sedation
- Test degree of comfort by reducing inspiratory pressure by 50% for a few minutes
Withdrawal of Assisted Ventilation at the Request of a Patient with Motor Neurone Disease

Withdrawal of assisted ventilation at the request of a patient with MND

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 there has been opportunity to present the work at British Thoracic Society and home ventilation group meetings nationally. The Guidance is already endorsed by Hospice UK and the RCN and the GMC have affirmed it is consistent with standards of good practice. Broader endorsement is being sought to safeguard patients and families and support professionals.

The Guidance calls for ongoing collation of a core dataset

This audit aims to include patients with a breadth of diseases that require assisted ventilation and is not restricted to those with MND. Further information and instructions for this can be seen here Audit of Process and Outcomes. Data can be submitted by downloading and completing this PDF or contacting the Secretariat for a word or spreadsheet version to complete electronically. Once completed please email to LAR.ventilation@nhs.net or post to Professor Christina Faull, LOROS, Groby Road, Leicester LE3 9QE

Please contact the Secretariat for the Word and Excel versions of these documents.

The Secretariat also holds a list of people with experience who would be willing to support anyone who is undertaking this with a patient.

Withdrawal of Ventilatory Support at the Request of an Adult Patient with Neuromuscular Disease

Association for Palliative Medicine Position Statement  
November 2015
What now?

- Publish findings
- Revise Guidance
- Continue audit
- Evaluate family experience in more depth (research)
Thank you

• Families involved in the research
• Kay Phelps, Emma Regen, Idaliza Nukis
• Guidance and Audit groups
• LOROS and MNDA funders