Association for Palliative Medicine Position Statement

APM position on Withdrawal of Ventilatory Support for Respiratory Failure at the Request of an Adult Patient

This statement intends to clarify the legal and ethical position for the care of patients in the UK who request that their ventilatory support be withdrawn; it also considers some appropriate aspects of clinical care.

1. The Association for Palliative Medicine is an organisation of over 1000 specialist doctors working in hospices, hospitals and the community.

2. A patient shown to have capacity can decline any potentially life-prolonging or medical treatment.

3. In law a refusal of a medical treatment by a patient who has capacity for that decision must be respected and complied with. To continue medial treatments that the patient does not want is to give treatment without consent and legally constitutes a battery.

4. Ventilation, whether invasive and delivered through a tracheostomy, or non-invasive and delivered by a mask or other equipment, is a medical treatment.

5. A patient with capacity to make such a decision may either refuse ventilation or ask that it be withdrawn, either at the time or by an advance decision to refuse treatment (ADRT).

6. Withdrawing a medical treatment that the patient no longer wants, such as ventilation, even if life is shortened thereby, is not assisted suicide or euthanasia because the intention is not to end life.

7. A patient dies under such circumstances from the consequences of overwhelming disease.

8. Patients and clinicians should openly discuss their thoughts and concerns about ventilation and quality of life. These discussions involving the patients, their family and the multidisciplinary team should begin before ventilation starts and continue through the illness.

9. Discussion of factors leading to the decision to stop ventilation should be open and thorough, seeking to identify any potential for alternative decisions and to minimise the impact of such a decision on family members.

10. Assessment of capacity to make the decision to stop ventilatory support is mandatory.

11. The clinical conditions where ventilation is appropriate are also conditions where patients often cannot physically withdraw ventilation themselves and so it will need to withdrawn by others, such as the medical team responsible.

12. Withdrawing ventilation may lead to distressing symptoms that require anticipatory and timely treatment with appropriate doses of medications such as sedatives and opioids targeted at relieving these symptoms. As with all good practice in palliative care, the intent is solely to ameliorate symptoms.

13. This area of care is challenging and requires excellence in multidisciplinary working and clinical leadership. Specialist input from palliative care and support for members of the team is likely to be important.

14. The GMC guidance *Treatment And Care Towards The End Of Life: Good Practice In Decision Making* (2010) provides more detail including how to conduct this decision making in the context of conflict, disagreement and questions with respect to mental capacity and in particular the value of gaining a second opinion in these cases.

The following guidance is available:

Guidelines for withdrawing ventilation (NIV) in patients with MND. Leicestershire and Rutland MND Supportive and Palliative Care Group. 20 November 2011 reviewed August 2014.

Guidelines for withdrawing Non-Invasive Ventilation (NIV) at End of Life. University Hospitals of North Staffordshire. Available at:
http://www.palliativedrugs.com/download/120517_Guidelines%20for%20withdrawing%20NIV.pdf

St Wilfrid's Hospice, Chichester. Clinical guideline No 9b. Withdrawing Non-Invasive Ventilation from MND patients 2009

The statement draws on the following literature:

Berger JT. 2012. Preemptive use of palliative sedation and amyotrophic lateral sclerosis. J Pain Symptom Manage 43; 802-5. doi: 10.106/j.painsymman.2011.10.012

Borasio GD, Voltz R. 1998. Discontinuation of mechanical ventilation in patients with amyotrophic lateral sclerosis. J Neurology 245: 717-22

Dreyer PS, Fielding M, Klitnaes CS, Lorenzen CK. 2012. Withdrawal of invasive home mechanical ventilation in patients with advanced amyotrophic lateral sclerosis: ten years of Danish experience. J Palliat Med 15: 205-9

Eng D. 2006. Management Guidelines for motor neurone disease patients on non invasive ventilation at home. Palliat Med 20: 69-79

Goldblatt D, Greenlaw J. 1989. Starting and stopping the ventilator for patients with amyotrophic lateral sclerosis. Neurologic Clinics 7: 789-805

Heffernan C, Jenkinson C, Holmes T, Macleod H, Kinnear W, Oliver D, et al. 2006. Management of respiration in MND/ALS patients: an evidence based review. Amyotroph Lateral Scler 7: 5-15

Le Bon B, Fisher S. 2011. Case report: Maintaining and withdrawing long-term invasive ventilation in a patient with MND/ALS in a home setting. Palliat Med 25: 262-5

NICE Clinical Guideline 105: Motor Neurone Disease; the use of non-invasive ventilation in the management of motor neurone disease. NICE July 2010

Oliver D, Faull C. 2013. Non-invasive ventilation in amyotrophic lateral sclerosis/motor neurone disease. Minverva Pneumologica 5: 27-38

Polkey MI, Lyall RA, Davidson AC, Leigh PN, Moxham J. 1999. Ethocal and clinical issues in the use of home non-invasive mechanical ventilation for the palliation of breathlessness in motor neurone disease. Thorax 54: 367-71

July 2013
(Review date: July 2016)