



Association for Palliative Medicine

Association for Palliative Medicine Position Statement

Withdrawal of ventilatory support at the request of an adult patient with neurological or neuro-muscular disease.

This statement intends to set-out the legal and ethical position for the care of patients with neurological or neuro-muscular conditions in the UK who request that their ventilatory support be withdrawn. Whilst the ethical principles are generic and applicable across the UK, the law in relation to mental capacity differs between England and Wales combined, and Scotland. The position statement is not a clinical guideline.

1. In UK law a refusal of a medical treatment by a patient who has capacity for that decision, must be respected and complied with, even if to comply with this refusal could lead to significant harm to the patient, including to their death. To continue medical treatments that a patient does not want is to give treatment without consent and legally constitutes a criminal offence of battery or a tort in civil law justifying financial compensation.
2. Ventilation, whether invasive and delivered through a tracheal tube, or non-invasive and delivered by a mask or other equipment, is a medical treatment.
3. A patient with capacity to make such a decision may either refuse ventilation or ask that it be withdrawn
4. A patient with capacity may also make an advance decision to refuse treatment (ADRT) to be implemented at a future point when capacity is lost and the specified circumstances for the refusal become applicable.
5. Whilst the timing of death may become a medically manipulated variable in these circumstances, the cause of death from a medical perspective remains the advanced neurological disease, and the classification of the death should be natural causes for the purposes of registration of the death from the perspective of either coroner or the law (except in circumstances where the disease itself requires different).
6. Withdrawing a medical treatment that a patient with capacity no longer wants, even if this is considered life-sustaining, is not assisted suicide.
7. Withdrawing a medical treatment from a patient who no longer has capacity, but who whilst having capacity made an ADRT which is specific in this regard and valid for these particular circumstances, is not euthanasia even if the medical treatment is life-sustaining.

8. Withdrawing a medical treatment from a patient who no longer has capacity, on the advice or request from an individual with lasting power of attorney for personal welfare (LPAPW), including decisions on life-sustaining medical treatment, and where on multidisciplinary review this request meets 'best interests' criteria, it is not euthanasia even if the medical treatment is life-sustaining.
9. Withdrawing a medical treatment from a patient who no longer has capacity but who has not made an ADRT or appointed an LPAPW, is a conventional 'best interests' determination the principles of which are set out within the MCA 2005 and refined within more recent case law.
10. Patients and clinicians should openly discuss their thoughts and concerns about ventilation and quality of life, and the circumstances in which a life sustained by ventilatory support would become intolerable or unacceptable. These discussions involving the patient, their family and the multidisciplinary team preferably should begin before ventilation starts and continue throughout the duration of the illness.
11. Discussion of factors leading to the decision to stop ventilation should be open, without coercion and thorough, seeking to identify any potential for alternative decisions and to minimise the impact of such a decision on family members. Ideally such discussion should be with the individual patient, family and healthcare team members, with these key people together.
12. Assessment of capacity to make the decision to stop ventilatory support is mandatory. As a matter of routine it should be a practitioner familiar with the issues who is assessing capacity for decision-making on those issues. Given the challenges in such decisions, and in the enactment of Advance Decisions to Refuse Treatment, it may sometimes be advisable to involve more than one appropriately trained clinician in assessing the patient's capacity, and to gather feedback from the multi-professional team and the family regarding the consistency of the patient's wishes. Rarely this may require additional expertise such as that of a psychiatrist to determine whether there is an identifiable and treatable mental health disorder compromising capacity.
13. The clinical conditions where ventilatory support is required to sustain life also involve conditions where patients often cannot physically withdraw ventilation themselves and so it will need to be withdrawn by the clinical team.
14. 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 must be solely to avoid or ameliorate symptoms of discomfort or distress. Relieving a patient of discomfort and distress is a fundamental medical responsibility and is not a modifier of the cause of death as set out above.
15. This area of care is challenging and requires excellence in multidisciplinary working and clinical leadership. Input from specialist palliative care will be helpful and support for members of the team is important.
16. 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

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

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 relevant law

Re B (Adult, refusal of medical treatment) [2002] EWHC 429 (Fam) 2 All ER449, Right of a patient who has capacity to refuse life-prolonging treatment:

Mental Capacity Act 2005: <http://www.legislation.gov.uk/ukpga/2005/9/contents> (England and Wales)

Re C (Adult refusal of treatment) [1994] 1 All ER 819

R v Bodkin Adams [1957] CLR 365 (Duty to relieve pain; 'if the purpose of medicine, the restoration of health, can no longer be achieved there is still much for a doctor to do, and he is entitled to do all that is proper and necessary to relieve pain and suffering, even if the measures he takes may incidentally shorten life')

House of Lords debate re Annie Lindsell *Hansard* HL 721-724 (Nov 20 1997) (duty to relieve suffering and distress at the end of life with particular reference to MND)
http://www.publications.parliament.uk/pa/ld199798/ldhansrd/vo971120/text/71120-18.htm#71120-18_head0

Adults with Incapacity (Scotland) Act 2000: <http://www.legislation.gov.uk/asp/2000/4/contents>

Proposed new mental capacity legislation (Northern Ireland)
<http://www.dojni.gov.uk/Consultation-on-proposals-for-new-Mental-Capacity-Legislation-for-Northern-Ireland>

Guidance from the BMA, Department of Health and GMC

BMA: Withholding and Withdrawing Life-prolonging Medical treatment: Guidance for decision making. 3rd edition 2007. Blackwell Publishing.

Department of Health. Reference Guide to consent for examination or treatment. 2nd edition 2009
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/138296/dh_103653_1_.pdf

GMC Consent guidance: patients and doctors making decisions together. 2008 Legal Annex- Common Law.
http://www.gmc-uk.org/guidance/ethical_guidance/consent_guidance_common_law.asp#Refusal

GMC Treatment and care towards the end of life: good practice in decision making. 2010. http://www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp

The following guidance on withdrawal of ventilation support is available:

Guidelines for withdrawing ventilation (NIV) in patients with MND. Leicestershire and Rutland MND Supportive and Palliative Care Group 20th reviewed January 2014 . Available at
http://www.loros.co.uk/media/uploads/files/healthcare/withdrawing_non-invasive_ventilation_pathway_guidelines_reviewed_jan_2014.pdf

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. Available at

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

[http://www.mndassociation.org/Resources/MNDA/Migrated%20Resources/Documents/C/Clinical%20guidelines%20withdrawing%20NIV%20for%20MND%20Patients%20St%20Wilfridand39s%20Hospice%20Chicester%20\(19\)_1827.pdf](http://www.mndassociation.org/Resources/MNDA/Migrated%20Resources/Documents/C/Clinical%20guidelines%20withdrawing%20NIV%20for%20MND%20Patients%20St%20Wilfridand39s%20Hospice%20Chicester%20(19)_1827.pdf)

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: 10.1016/j.jpainsymman.2011.10.012.

Borasio GD, Voltz R. 1998. Discontinuation of mechanical ventilation in patients with amyotrophic lateral sclerosis. *J Neurology* 245; 717-722

Dreyer PS, Felding M, Klitnæs 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.

Edwards M. 2005. Opioids and benzodiazepines appear paradoxically to delay inevitable death after ventilator withdrawal. *J Palliat Care* 21: 299302.

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

Faull C, Rowe-Haynes C, Oliver D (2014) The Issues for Palliative Medicine Doctors Surrounding the Withdrawal of NIV at the Request of a Patient with MND: A Scoping Study. *BMJ Support Palliat Care* 4:43-49

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.

Martin NH, Landau S, Janssen A, et al . Psychological as well as illness factors influence acceptance of non-invasive ventilation (NIV) and gastrostomy in amyotrophic lateral sclerosis (ALS): a prospective population study. *Amyotroph Lateral Scler Frontotemporal Degener.* 2014 Sep;15(5-6):376-87. doi: 10.3109/21678421.2014.886700.

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. *Minerva Pneumologica* 5:27-38

Phelps K, Regen E, □Oliver, McDermott □Faull, C 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. (in press March 2015)

Polkey MI, Lyall RA, Davidson AC, Leigh PN, Moxham J. 1999. Ethical and clinical issues in the use of home non-invasive mechanical ventilation for the palliation of breathlessness in motor neurone disease. *Thorax* 54; 367-371