



ASSOCIATION FOR PALLIATIVE MEDICINE POSITION STATEMENT  
NOVEMBER 2015  
(Reviewed November 2024)

**WITHDRAWAL OF VENTILATORY SUPPORT AT THE REQUEST OF AN  
ADULT PATIENT WITH NEURO-MUSCULAR DISEASE**

This statement intends to set out the legal and ethical position for the care of patients with neuro-muscular conditions in the UK who request that their ventilatory support be withdrawn. While the ethical principles are generic and applicable across the UK, the law in relation to mental capacity differs between England and Wales combined, Northern Ireland and Scotland. For simplicity this document draws on the 2005 Mental Capacity Act (MCA) for England and Wales.

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. Assisted 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 A patient with capacity to make such a decision may either refuse assisted ventilation or ask that it be withdrawn.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 will be influenced by the withdrawal of ventilation 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<sup>1</sup> for the purposes of issuing a medical certificate of cause of death and subsequent registration of the death by the next of kin. Such a certificate may read for example:

1a ventilatory failure (due to) 1b advanced motor neurone disease.

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<sup>1</sup>In neurological conditions where the origins of the disability are 'unnatural', such as ventilator-dependent high traumatic spinal cord injury, the death is reportable to the coroner

6. When a patient with capacity has decided that the burdens of continued medical treatment outweigh the benefits, this is distinct in law from a decision to foreshorten their life by suicide or 'self-neglect'.
7. Withdrawing a medical treatment that a patient with capacity no longer wants, even if this is considered life-sustaining, is not assisted suicide.
8. Withdrawing a medical treatment from a patient who no longer has capacity, but who while having capacity made an advance decision to refuse treatment (ADRT) which is specific in this regard and valid for these particular circumstances, is not euthanasia even if the medical treatment is life-sustaining.
9. Withdrawing a medical treatment from a patient who no longer has capacity, on the advice or request from an appointed attorney, including decisions on life-sustaining medical treatment, and where on multidisciplinary review this request meets 'best interests' criteria, is not euthanasia even if the medical treatment is life-sustaining.
10. Withdrawing a medical treatment from a patient who no longer has capacity but who has not made an ADRT or appointed an attorney, is a conventional 'best interests' determination; the principles of which are set out within the Mental Capacity Act 2005 and refined within more recent case law.
11. Patients and clinicians should openly discuss their thoughts and concerns about assisted 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 (with due regard for confidentiality) and the multidisciplinary team preferably should begin before assisted ventilation starts and continue throughout the duration of the illness.
12. Discussion of factors leading to the decision to stop assisted 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.
13. 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.
14. The clinical conditions where ventilatory support is required to sustain life also involve conditions where patients often cannot physically withdraw assisted ventilation themselves and so it will need to be withdrawn by the clinical team.
15. Withdrawing assisted 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.

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Position statement also referenced in the Withdrawal of NIV in MND patients guidance



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16. 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.
  
17. 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 relevant law

1. 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:
2. Mental Capacity Act 2005: <http://www.legislation.gov.uk/ukpga/2005/9/contents> (England and Wales)
3. Re C (Adult refusal of treatment) [1994] 1 All ER 819
4. *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')
5. 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](http://www.publications.parliament.uk/pa/ld199798/ldhansrd/vo971120/text/71120-18.htm#71120-18_head0)
6. Adults with Incapacity (Scotland) Act 2000: <http://www.legislation.gov.uk/asp/2000/4/contents>
7. 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, NMC and RCN

8. Department of Health. Reference Guide to consent for examination or treatment. 2<sup>nd</sup> edition 2009. [gmc-guidance-for-doctors---decision-making-and-consent-english\\_pdf-84191055.pdf](http://www.gmc-uk.org/guidance/ethical_guidance/consent_guidance_common_law.asp#Refusal)
9. English, V. *Withholding and Withdrawing Life-prolonging Medical treatment: Guidance for decision making*. 3<sup>rd</sup> edn 2007. London, British Medical Association with Blackwell Publishing.
10. 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](http://www.gmc-uk.org/guidance/ethical_guidance/consent_guidance_common_law.asp#Refusal)
11. GMC Treatment and care towards the end of life: good practice in decision making. 2010. [Treatment and care towards the end of life - professional standards - GMC](http://www.gmc-uk.org/guidance/ethical_guidance/treatment_and_care_towards_the_end_of_life_professional_standards_gmc)
12. NMC The Code: Professional standards of practice and behaviour for nurses and midwives . 2015 [www.nmc.org.uk/standards/code/](http://www.nmc.org.uk/standards/code/)
13. RCN Delegating record keeping and countersigning records. 2012 [www.rcn.org.uk/\\_data/assets/pdf\\_file/0005/486662/004\\_337.pdf](http://www.rcn.org.uk/_data/assets/pdf_file/0005/486662/004_337.pdf)
14. RCN Accountability and delegation: A guide for the nursing team . 2015. [www.rcn.org.uk/\\_data/assets/pdf\\_file/0006/627216/004852\\_HP-A-and-D\\_pocketguide\\_June2015.pdf](http://www.rcn.org.uk/_data/assets/pdf_file/0006/627216/004852_HP-A-and-D_pocketguide_June2015.pdf)

## The following guidance has informed this document

Cherny, N.I. and Radbruch, L. (2009) 'European Association for Palliative Care (EAPC) recommended framework for the use of sedation in palliative care', *Palliative medicine*, vol. 23, pp581-593.

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Guidelines for withdrawing Non-Invasive Ventilation (NIV) at End of Life. University Hospitals of North Staffordshire. Available at [www.palliativedrugs.com/download/120517\\_Guidelines\\_for\\_withdrawing\\_NIV.pdf](http://www.palliativedrugs.com/download/120517_Guidelines_for_withdrawing_NIV.pdf) (Accessed 08 September 2015)

Leicestershire and Rutland MND Supportive and Palliative Care Group (2014) *Guidelines for Withdrawing Ventilation (NIV) in Patients with MND* [Online]. Available at [www.mndassociation.org/wp-content/uploads/2015/02/leicestershire-and-rutland-pathway-and-guidelines-for-withdrawing-niv.pdf](http://www.mndassociation.org/wp-content/uploads/2015/02/leicestershire-and-rutland-pathway-and-guidelines-for-withdrawing-niv.pdf) (Accessed 08 September 2015).

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