

# End of life decision making with Motor Neurone Disease patients on Home Mechanical Ventilation



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## Background

There is currently little published evidence about what it is like to die with MND/ALS using assisted ventilation, or to have ventilation withdrawn. Withdrawing ventilation is stressful and challenging for health professionals but we do not know what patients or family members think about this, how they make decisions about staying on or stopping ventilation, what their concerns might be or what the longer-term impact is for families. UK guidance recommends that a care plan be put in place prior to starting ventilation, with provision to regularly discuss continuation or withdrawal.

## Method

- Interviews with 12 bereaved family members
- Conducted either via a video platform or telephone
- Thematic analysis was used
- Part of a larger, ongoing, UK study to explore patient and family experiences of making decisions about using ventilation at the end of life.

*The complexities of it, because it was end of life, they sent two doctors round and our feelings at the time were that we should just take his mask off and let him just go peacefully. Because there wasn't an advanced directive in place they weren't happy to do that. ... I did have quite a lot of issues with not being able to do it sooner ....I felt that time was right the night before. (Family Member 102)*

*I think the feeling when he tried to breathe without the ventilation, he'd been so frightened that he couldn't agree to that being removed (Family Member 101)*

## FINDINGS:

- There were few accounts of discussions about end of life decision-making in relation to ventilation.
- A number of patients did not want to officially document their wishes but would make certain aspects known to family members over time.
- Family members reported having little knowledge or understanding of how dying would occur and wanted more information about this phase.
- Some participants felt the ventilation had kept the patient's body alive beyond the point of a natural death, blurring the nature of the death.

*I just sat there, watching and shaking uncontrollably. There was a particularly upsetting point when his body involuntarily moved, sort of curled up a bit, which I asked about and the medics said it was just something that happens but that he had already passed. (Family Member 110)*

