

# Responsibility in caring for those with MND and ventilation at the end of life: bereaved family member perspectives



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## Background

Little is known about the use of ventilation for MND/ALS at the end of life or the impacts of such life sustaining treatments on the family members often expected to maintain and manage them at home.

## Method

- Interviews with 36 bereaved family members
- Conducted either via a video platform, telephone or email
- Thematic analysis was used
- Part of a larger UK study to explore patient and family experiences of making decisions about using ventilation at the end of life.

*I think people who deal with ALS, MND, ...I think you get a bit of post-traumatic stress, because you relive all [that has] gone on and that they went through and you question everything that you've done. (Family member 06)*

*To keep changing the mask and you knew you had to stop the machine, change the mask and wash his face ...Get the mask on and then, even though the machine would work you just prayed to God that it would start again ...it just panicked you because I felt so responsible even though I knew it was inevitable. It was just, that's the scariest bit for me ...because I felt I was turning off the piece of equipment that was really helping [him]. (Family member 13)*

## FINDINGS:

- All participants had experiences of patients dying either with ventilation in place or after withdrawal.
- Managing ventilation, particularly alongside other complex interventions, could have significant impact on the wellbeing of family members.
- The weight of responsibility resulted in physical and mental exhaustion and reports of post-traumatic stress-like symptoms long into bereavement.
- Family members received little training or support.
- Some felt responsible for contributing to a final decision about ventilation use during the dying process.

The provision of support from knowledgeable healthcare teams can significantly lift this weight of responsibility and have a positive impact on the perceived quality of death.

*I was fortunate that they let me have a room at (hospice), so I was there 24 hours a day with her for the last week. But not having the responsibility of washing her but keeping an eye on her all the time. I felt that if there was something I was able to call the nurses and things like that and say look, and not having to worry about anything else but just be with her. That was very special in a way. (Family member 08)*

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