Withdrawal of Ventilation at the Request of a Patient with Motor Neurone Disease (MND)

A Retrospective Exploration of the Experience of Doctors, Non-Medical Health Professionals and Close Family

**BACKGROUND**

Some people with MND who use NIV become very dependent on it, requiring constant use to alleviate symptoms. A few take a decision to stop the NIV and ask their clinical team for help in managing the process and the symptoms that happen when the NIV mask is left off.

The NICE guidance in England and Wales on the use of NIV in MND (2010) identifies the lack of any clarity in the most effective and acceptable method of this withdrawal and how this process should be facilitated and managed.

We report here findings from interviews which explored the experiences of doctors in England and Wales who had supported people who had asked for the withdrawal of the NIV.

**METHODS**

All doctors who volunteered from the specialties of neurology (1), family (GP) (3) and respiratory medicine (3) were interviewed together with purposively sampled respondents from specialty of palliative medicine (13) looking for breadth of geographical practice and place of NIV withdrawal (home, hospice, hospital, care home). A qualitative, exploratory approach was used, transcripts analyzed thematically using a grounded theory approach.

**RESULTS**

These events were rare but extraordinarily memorable with explicit detail of aspects recalled from several years past. The emotionality and the tensions of the situation were especially vivid whereas the logistics were more variably recalled. Doctors carried these experiences with them. Few had opportunity to share this area of practice, their experience and persisting reflections with colleagues. Isolation and lack of support was a frequent experience. The clarity of the ethical and clinical decision making was in contrast to the multilayered and conflicting feelings doctors experienced in carrying out the patients wishes. The role of the different doctors involved with a patient varied case by case. Doctors described examples of both collaborative and less integrated decision making:

- I did the medication……. I had more experience of seeing that sometimes they need medication, sometimes they didn’t, and I had in my head some experience that was perhaps difficult to articulate to others exactly what doses.  
  [Palliative care Consultant]

- It wasn’t really me just making that decision on my own I suppose so in some respects that was quite helpful for me.  
  [GP]

- I kind of feel a bit angry about it …I ended up running the show and I don’t think it was fair on me or the patient or the family that somebody who effectively should have been learning about it was doing it.  
  [GP]

- Although I believe in that ethically in a detached way when you’re actually there and you feel like you’re taking a life it’s quite difficult.  
  [GP]

- I also don’t want him to live in this bloody living hell and I do feel he has a right to determine his future but actually when it comes down to it, I don’t want – it terrifies me, it bloody terrifies me.  
  [GP]

- It’s the first time I’ve ever had a motor neurone case, it’s the first time I’ve ever had a NIV case, it’s the first time I’ve ever done an advance decision ….. I just don’t feel I got that help  
  [GP]

- I did feel quite alone in it… I felt very responsible for the whole thing but yet, you know, in some ways felt like I didn’t know what I was doing.  
  [Palliative Care Consultant]

- So you ring the MDU expecting to be able to rely on their advice …..but this GP was told that, you know, you could be sued for manslaughter  
  [Palliative Care Consultant]

- Nurses have been told …. that they must not be involved in any way in this act otherwise they may be charged with murder.  
  [Palliative Care Consultant]

**CONCLUSION**

This is a lonely and uncomfortable experience for doctors. The absence of guidance both practical and professional was a strong feature. There is a need to build consensus about this area of care amongst those involved in discussions as well as those involved at the time of withdrawal.