Who will benefit from tracheostomy ventilation in motor neuron disease?

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The decision when to recommend tracheostomy ventilation in motor neuron disease (amyotrophic lateral sclerosis) has always been difficult. At one extreme is the view that when spontaneous ventilation or non-invasive ventilation is inadequate, a tracheostomy will save the patient’s life and lead to prolonged survival. This view has been more widely held in the USA than elsewhere. In the UK, a common position is the opposite, with a nihilistic attitude towards invasive respiratory treatment. The rationale behind this is that it is too intrusive, both for the patient and for the family and carers, and that once a tracheostomy is needed, palliative care is more appropriate.

Not surprisingly, there has been a wide geographical variation in the proportion of patients who proceed to a tracheostomy, and the review by Sancho et al is timely. The authors describe a 9-year experience in a specialist respiratory care unit where the issues surrounding tracheostomy ventilation were openly discussed with each patient who might benefit from it. Out of 76 subjects 38 refused. Unfortunately, no further data are provided about these patients to compare their outcomes in terms of quality of life with the 38 who underwent a tracheostomy but their mean survival was only 0.83 months.

Interestingly, over half of those who underwent a tracheostomy did so during an acute severe chest infection in which non-invasive ventilation was either ineffective or not indicated. These patients were transferred from endotracheal intubation to tracheostomy ventilation. The indications were otherwise untreatable ventilatory failure or the need for access to tracheobronchial secretions during and after the infection. The mean survival after tracheostomy was 10.76 months, which was similar to the mean survival when tracheostomy was carried out electively.

As has also been reported in a recent study, some of these patients eventually did not require continuous ventilatory support, but there is no mention of whether any could be weaned onto non-invasive ventilation once they recovered from their acute illness. Another report, however, suggests that almost half of those who undergo tracheostomy ventilation in this situation can eventually be weaned onto non-invasive support. Their survival is as good as those who still require tracheostomy ventilation but they are more likely to be able to return home.

These encouraging findings suggest that there is a need for a re-appraisal of the management of severe chest infections in motor neuron disease. A much more active approach needs to be taken by intensivists, neurologists and respiratory physicians involved in their care than has been the standard practice in the past.

The indications for elective tracheostomy ventilation were either an inability to provide adequate ventilatory support non-invasively or the need to protect the airway despite the use of manually assisted coughing. It has been demonstrated that non-invasive systems can almost invariably adequately ventilate the subject and it is a defective swallow or cough that usually leads to the need for a tracheostomy apart from the convenience of being ventilated through this route if respiratory support is needed virtually or completely continuously.

Complications of the tracheostomy itself were infrequent, but almost one-third of the patients required admission for treatment of a chest infection despite their tracheostomy. There was only one death from a respiratory infection in this series and overall 78.9% of patients survived for 1 year. Interestingly, nine patients died suddenly raising the possibility that there is a defect in sympathetic activation in response to stress as part of the neurological deficit in motor neuron disease.

These findings present an optimistic view of tracheostomy ventilation, but quite frequent psychiatric assessments were required, mainly for anxiety and depression. It could be argued that depression is a feature of motor neuron disease and the limitations that it causes occur even without a tracheostomy. A control group would be required to assess whether tracheostomy actually leads to more or less anxiety and depression. Their incidence and severity appeared to be related more to the degree of social support available, the coping capacity of the individual and the loss of independence rather than to the more direct physical effects of the tracheostomy itself. There is also no doubt that tracheostomy ventilation requires more assistance from the family and carers than non-invasive systems. Its impact on the carers and family needs to be carefully assessed and further studies of this are required.

Although there was a shared approach to the decision to start tracheostomy ventilation, this report gives no data about why 38 subjects refused this treatment or why the other 38 accepted it. Previous studies have shown that young males are more likely to accept a tracheostomy than older females. This may be related to a common perception that a tracheostomy is a life-saving operation in contrast to the apparently more modest effect of an improvement in the quality of life that can be achieved by non-invasive ventilation. The individual’s values such as autonomy and communication, and fears such as of choking and of dying are also important in deciding whether or not to undergo a tracheostomy. Advanced directives have not proved as useful in practice as was anticipated and do not appear to have been of value in this study. It is hard for the individual to anticipate how he or she will feel at the time that a tracheostomy is required. This may not seem attractive early in the natural history of the condition but later, when faced with the situation, many people will take up the offer of a life-saving treatment rather than agreeing to imminent death.

There is no simple answer to when or whether tracheostomy ventilation should be offered to those with motor neuron disease. Whether or not the chance of an increased survival outweighs the intrusiveness of the treatment depends on how the patient values the various aspects of the quality and quantity of life and assesses the impact of the illness and its treatment on family, friends and carers.
While some of these issues are primarily medical, others depend on the individual patient’s perceptions. It is only when both doctor and patient understand each other’s points of view that the correct decisions will be made.

**Competing interests** None.

**Provenance and peer review** Commissioned; internally peer reviewed.

*Thorax* 2011; ■:1–2. doi:10.1136/thoraxjnl-2011-200728

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Thorax published online August 3, 2011

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