



Editorial

Tracheotomy in Amyotrophic Lateral Sclerosis: The Argument in Favor[☆]



Traqueotomía en enfermos con ELA: pro

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There is still no cure for amyotrophic lateral sclerosis (ALS), but substantial changes in its treatment have been introduced in recent years. At the end of the last century, neurologists were clearly reluctant to provide ALS patients with therapeutic alternatives other than palliative care,¹ and even in this century, some actively discouraged the use of tracheostomy in these patients.² Nowadays, however, the management of ALS has become a multidisciplinary process in which, thanks to research and innovation, pulmonologists offer therapeutic options that are effective in prolonging life and improving conditions during the course of the disease.

Given that all scientific societies include tracheotomy in their ALS decision Trees,³ the key question should no longer be “tracheotomy in ALS, yes or no?”, and the following two questions should be asked: Do our department and hospital have the specific resources and the appropriate organization to be able to offer tracheotomy to patients who, after being fully informed, wish to continue living when non-invasive management has failed? And are we able to convey to the patient and their family what is involved in living with a tracheotomy, so that they can make an informed decision? Real-world experience shows that in too many cases, ALS tracheotomies performed in a department depend less on the availability of resources of the department, and more on the personal interests of some of its physicians.

Obviously, no-one wants to resort to tracheostomy, but it must be remembered that this is a real alternative for patients with a desire to live (1-year survival in our experience was 79%),⁴ and a key part of the continuum of care in the management of respiratory problems in ALS. In this complex process, clinical monitoring and functional assessment determine when non-invasive therapeutic strategies are no longer sustainable and when they should be replaced by invasive procedures or intensive palliative care.^{5,6}

In the absence of official guidelines to ensure that a particular unit has the knowledge, skills, and technology to guarantee excel-

lence in non-invasive management and to qualify it to respond with the same quality and safety to the needs inherent in tracheotomy, the British Complex Home Ventilation system⁷ or the SEPAR High Complexity Units criteria⁸ can serve as a model for the human and technical resources needed to optimize the portfolio of services that must, necessarily, include research and teaching. When these units work closely with critical care units in prolonged weaning procedures,⁹ their efficiency and sustainability improve, they gain relevance in the hospital setting, and patients are freed from the distressing environment of a critical care room. Moreover (and very importantly), treating long-term critical patients helps the staff in these units to improve their skills in managing complex situations.

If the first question was whether we are in a position to offer a tracheotomy, the second, equally relevant, question is how can the team help the patient and the family make such an important decision? Relationship skills are crucial in this decision-making process. Conversations should be conducted with clarity and confidence, and the help of an expert psychologist can greatly facilitate the timing and *tempo* of the information given and minimize distress.¹⁰ To help people who are unfamiliar with this technique understand the nature of this process (and this may be the case for some readers), it is necessary to convey the concept that the tracheostomy is not an end in itself, but a way to achieve safe access to remove secretions and preserve alveolar ventilation when this can no longer be achieved in a non-invasive manner. Therefore, patients do not reject or refuse the actual tracheotomy procedure; what they might reject are certain states of health that are part and parcel of maintaining life after a tracheostomy. In general, they choose tracheotomy when they believe that their subsequent condition will not deprive them of the capabilities that they consider “minimum” for continuing to live, and also when they are confident that if their situation changes, they may revoke their previous decision and request the withdrawal of life support with the assurance that the process will be undertaken with the care and quality it merits. During this step, advance healthcare directives must be drawn up to prepare for especially complicated situations, such as the development of frontotemporal dementia¹¹ or locked-in syndrome.¹²

Patients need to be aware that tracheotomy ventilation will be a massive burden for the family,¹³ but also that it is unlikely to

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increase their levels of anxiety and depression (or those of the main caregiver) if support from the health and social services, including psychological help, is optimal.¹⁰ It has been known for years (and we too have observed it in our environment) that with proper care most respondents would be tracheotomized again, and that most family members, in spite of recognizing the difficulty of the situation, are in agreement with the patient's initial decision.^{14,15} This confidence that the decision was the right one validates the procedure for those who chose it, but does not alleviate in any way the hardships suffered by the patient and their family in their daily routine. A quadriplegic patient receiving ventilation by tracheotomy is the paradigm of fragility and dependence, and their caregivers take on not only their management, but also the responsibility for caring for them with sensitivity and empathy, and protecting them from those health system routines that add considerable distress to their daily life.

The quality of care available for ALS patients has improved immensely, but equitable access to such care still leaves a lot to be desired. A step toward good clinical practice and equity of access may come with the creation of clinical guidelines, reflecting consensus recommendations from experts from different specialties involved in the management of these patients (mainly respiratory medicine, intensive care, family medicine and home hospitalization services). Nevertheless, excellence in care will not be a reality until the State undertakes to resolve a situation in which some patients are prevented by a lack of resources from choosing the (desired) option to continue with life.

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