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## REVISÃO

### Early gastrostomy associated with speech therapy in patients with amyotrophic lateral sclerosis

#### *Benefícios da gastrostomia precoce associada a terapêutica fonoaudiológica em pacientes com esclerose lateral amiotrófica*

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## Resumo

Esclerose Lateral Amiotrófica (ELA) é uma doença degenerativa que cursa com a deterioração dos neurônios motores. O início do comprometimento clínico pode ser bulbar com o tempo médio de vida após os primeiros sintomas de 2 à 5 anos, apresentando sérios distúrbios de deglutição, fala e respiração. Os transtornos de deglutição podem ocasionar desnutrição, desidratação, aspiração, desprazer, além de complicações mais graves como a pneumonia aspirativa e o óbito. Com a evolução da doença o paciente necessita de procedimentos que geram dúvidas nos profissionais e nos familiares como o momento correto de indicação do uso de vias alternativas de alimentação de longa duração denominada gastrostomia (GTT). O objetivo desse artigo é analisar o impacto da disfagia e o momento mais favorável para a colocação da gastrostomia. A colocação precoce da GTT pode auxiliar a evitar que o paciente se debilite clinicamente mais rapidamente, responda melhor as terapêuticas da equipe multidisciplinar e tenha mais conforto.

**Palavras-chave:** disfagia, nutrição enteral, gastrostomia, transtornos de deglutição, doença dos neurônios motores, esclerose amiotrófica lateral.

## Abstract

Amyotrophic Lateral Sclerosis (ALS) is a degenerative disease that occurs with the deterioration of motor neurons. The beginning of clinical impairment may be bulbar with the average life time, after the first symptoms, between 2 to 5 years, presenting serious swallowing, speech and breathing disorders. Deglutition disorders can lead to malnutrition, dehydration, aspiration, displeasure, and more serious complications such as aspiration pneumonia and death. With the evolution of the disease, the patient needs procedures that generate doubts in the professionals

and family, as the correct moment of indication of the use of alternative long-term feeding routes called gastrostomies (GTT). The objective of this article is to analyze the impact of dysphagias and the most favorable moment for the placement of gastrostomies. Early GTT placement may help prevent the patient from clinically debilitating more quickly, respond better to multidisciplinary team therapeutics, and feel more comfortable.

**Key-words:** dysphagia, enteral nutrition, gastrostomy, deglutition disorders, motor neuron disease, amyotrophic lateral sclerosis.

## Introduction

Amyotrophic lateral sclerosis (ALS) is a devastating degenerative disease with a strong impact on the quality of life of its patients and their families. After the final diagnosis, some issues are worth taking into consideration. Oral feeding difficulties, speech disorders, underfeeding, bronchopneumonias and the correct time to perform the long-term alternative feeding procedure such as gastrostomies (PEG - percutaneous endoscopic gastrostomy) and the questions that involve mechanical ventilation, that is especially invasive due to the need of performing tracheostomy, are issues that cause great doubts and disagreements not only for patients and their families, but also for the professionals who treat ALS [1]. In order to analyze the particular theme related to dysphagia, nutrition and the most favorable moment of placement of PEG, a literary research was carried out aiming at helping to elucidate specifically these questions.

## Review

Amyotrophic Lateral Sclerosis (ALS) is a neurodegenerative disease that occurs with the deterioration of motor neurons, and the most prevalent form presents signs of injury to lower motor neurons (amyotrophy), upper motor neurons (spasticity) and bulbar lesions causing severe speech and deglutition disorders. The average survival time after the onset of the first symptoms is two to five years [1,2].

As disease progresses and patients become more dependent, they and their families are impacted not only emotionally and socially, but also economically. However, although there is no curative treatment for ALS, adequate therapeutic measures capable of promoting quality of life for patients and safety for their families are not to be ruled out, as they are doing their best within the possibilities of the disease [1,2].

The pleasant experience of oral feeding involves all individuals from birth to the end of life. All societies associate food with one of the greatest pleasures of the human being guaranteeing the maintenance of life. Therefore, the swallowing disorders present in ALS are one of the symptoms that cause extreme concern. Dysphagia is the difficulty in swallowing related to the functioning of the oropharyngeal and oesophageal structures, making it difficult or impossible to safely, effectively and comfortably consume saliva, liquids and/or foods of any consistency, which can lead to malnutrition, dehydration, aspiration, discomfort and social isolation, in addition to more serious complications such as aspiration pneumonia and death [3].

The aim of clinical treatment for dysphagia is to provide safe deglutition through compensatory procedures, as well as myofunctional breathing [4] and learning techniques that encourage the proprioception, posture changes and oral deglutition maneuvers. Patients treated since early stages can develop muscle adaptive mechanisms and reduce the risk of tracheal aspiration even with serious muscle alterations. With the worsening dysphagia, it is necessary to indicate PEG as an alternative route [5].

Dysphagia has been one of the strong predictors of PEG acceptance, especially when it causes displeasure in the feeding [6] and in patients with a vital capacity of less than 50% [7]. Most teams consider the PEG indication a combination of factors such as respiratory decline, weight loss, dysphagia, and/or patient readiness [8]. However, these parameters have been reviewed and the search for better treatments has shown that the presence of the multidisciplinary team can prolong the life time with more quality [9,10]. The GEP has been used as a resource that brings more advantages to the patient who needs a medium or long term feeding supply [11]. It is considered the gold standard procedure of enteral nutrition in ALS [12].

Although there is no evidence that the use of PEG prolongs the life span the procedure performed early has been directly associated with the improvement of the patient's well-being, once it can maintain a partial oral route.

The insertion of PEG does not necessarily exclude oral feeding, but provides a way to administer medicines, hydration, food supplement, with the aim to stabilize the eutrophy [13]. The patient has autonomy to ingest food of his preference, with the consistency indicated by his speech pathologist as safe in the continuous swallowing assessments [3] and in the volume he wishes to ingest, since the indicated nutritional intake will be guaranteed through PEG [9]. By using this kind of conduct, it avoids that eating becomes a disorder with a consequent reduction in oral intake, which causes excessive weight loss, hypermetabolism, dehydration and malnutrition that can aggravate muscular atrophy, in addition to compromising the respiratory condition in a more significant way and the increase risk of other comorbidities [9,10]. Current guidelines are based on higher rates of post-procedure PEG complications in patients with ALS with advanced respiratory dysfunction, which led to a recommendation to perform the procedure before the vital capacity is <50% [10]. Therefore, it is very important to assess the patient when there is respiratory muscle weakness with loss of vital capacity. The insertion of GEP does not offer risk to the patient, but there is a need to make the procedure with ventilation monitoring [4].

The multidisciplinary management is essential in the treatment of patients with ALS. The PEG should be early, even before the severity of dysphagia [4]. The European consensus suggests the early insertion of PEG, even recognizing the difficulty that can be in the patient's adherence to this idea, especially in the absence of dysphagia [12].

The main benefits of early indication of PEG, even before the presence of severe dysphagia, is to prevent the patient from becoming clinically debilitated more rapidly, so as to respond better to speech and deglutition therapies as well as of the multidisciplinary team, and especially for the ALS patient to have a life as comfortable as possible.

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