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Nutrition in patients with amyotrophic lateral sclerosis

Nutrição do paciente com esclerose lateral amiotrófica

Nutrición del paciente con esclerosis lateral amiotrófica

Élida Naiane Sousa Machado[1], Angela Adamski da Silva Reis[1], Rodrigo da Silva Santos[1].

ABSTRACT

Objective: To review the literature on nutritional management in patients with Amyotrophic Lateral Sclerosis (ALS), with emphasis on strategies to prevent and treat malnutrition, as well as to discuss its relationship with patient survival. **Literature review:** Findings indicate that malnutrition in patients with ALS is multifactorial, being mainly associated with dysphagia, hypermetabolism, and reduced food intake. These factors interact with each other, resulting in negative energy balance, progressive weight loss, and worsening nutritional status. Strategies such as hypercaloric diets, food texture modification, and enteral nutrition are essential to ensure adequate intake and feeding safety. **Final considerations:** ALS significantly compromises patients' quality of life, with malnutrition and dysphagia being the most prevalent complications. Early nutritional intervention, combined with multidisciplinary follow-up, is essential to improve prognosis and promote well-being. Furthermore, there is a need for more standardized guidelines to optimize the nutritional management of these patients.

Keywords: Motor neuron disease, Malnutrition, Dysphagia, Nutrition.

RESUMO

Objetivo: Revisar sobre o manejo nutricional em pacientes com Esclerose Lateral Amiotrófica (ELA), com ênfase em estratégias para prevenir e tratar a desnutrição, além de discutir a relação entre a desnutrição e a sobrevida desses pacientes. **Revisão bibliográfica:** Os achados indicam que a desnutrição em pacientes com ELA é multifatorial, estando associada principalmente à disfagia, ao hipermetabolismo e à redução da ingestão alimentar. Esses fatores interagem entre si, resultando em balanço energético negativo, perda de peso progressiva e piora do estado nutricional. Estratégias como dietas hipercalóricas, modificação da consistência alimentar e uso de nutrição enteral mostram-se fundamentais para garantir aporte adequado e segurança alimentar. **Considerações finais:** Pode-se considerar que a ELA compromete significativamente a qualidade de vida dos pacientes, sendo a desnutrição e a disfagia as complicações mais prevalentes. A intervenção nutricional precoce, aliada ao acompanhamento multiprofissional, mostra-se essencial para melhorar o prognóstico e promover o bem-estar desses indivíduos. Contudo, observa-se a necessidade de diretrizes padronizadas que orientem de forma mais eficaz o manejo nutricional desses pacientes.

Palavras-chave: Doença do neurônio motor, Desnutrição, Disfagia, Nutrição.

[1] Núcleo de Pesquisas em Neurogenética (NeuroGene), Instituto de Ciências Biológicas (ICB), Universidade Federal de Goiás (UFG), Goiânia – GO.

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RESUMEN

Objetivo: Revisar la literatura sobre el manejo nutricional en pacientes con Esclerosis Lateral Amiotrófica (ELA), con énfasis en estrategias para prevenir y tratar la desnutrición, además de discutir su relación con la supervivencia de estos pacientes. **Revisión bibliográfica:** Los hallazgos indican que la desnutrición en pacientes con ELA es multifactorial, estando principalmente asociada con la disfagia, el hipermetabolismo y la reducción de la ingesta alimentaria. Estos factores interactúan entre sí, resultando en un balance energético negativo, pérdida de peso progresiva y deterioro del estado nutricional. Estrategias como dietas hipercalóricas, modificación de la consistencia de los alimentos y el uso de nutrición enteral son fundamentales para garantizar un aporte adecuado y la seguridad alimentaria. **Consideraciones finales:** La ELA compromete significativamente la calidad de vida de los pacientes, siendo la desnutrición y la disfagia las complicaciones más prevalentes. La intervención nutricional temprana, junto con el seguimiento multidisciplinario, es esencial para mejorar el pronóstico y promover el bienestar. Asimismo, se destaca la necesidad de directrices más estandarizadas para optimizar el manejo nutricional de estos pacientes.

Palabras clave: Enfermedad de la neurona motora, Desnutrición, Disfagia, Nutrición.

INTRODUCTION

Amyotrophic Lateral Sclerosis (ALS) is a Motor Neuron Disease (MND) and one of the major neurodegenerative diseases, alongside Parkinson's and Alzheimer's diseases (BRAZIL, 2021). Also known as Lou Gehrig's disease or Charcot´s disease, ALS was first described by Jean-Martin Charcot in 1874 (HIRAYAMA T, et al., 2023 and MAKSIMOVIC K, et al., 2023). The disease gained public attention in the early 1940s when baseball player Henry Louis Gehrig was diagnosed with ALS and subsequently died from its consequences (PAPE JA and GROSE JH, 2020).

ALS is a rare, rapidly progressive, and multisystem neurodegenerative disease that primarily affects adults. It is characterized by progressive damage and death of lower motor neurons located in the spinal cord and brainstem, which control voluntary muscles, as well as upper motor neurons located in the motor cortex. Degeneration of these neurons results in muscle weakness and atrophy (LIMA NS, et al., 2022; PROAÑO B, et al, 2024 and XU RS and YUAN M, 2021). Diagnosis remains challenging, as it requires exclusion of other diseases that may cause motor neuron degeneration (XU RS and YUAN M, 2021).

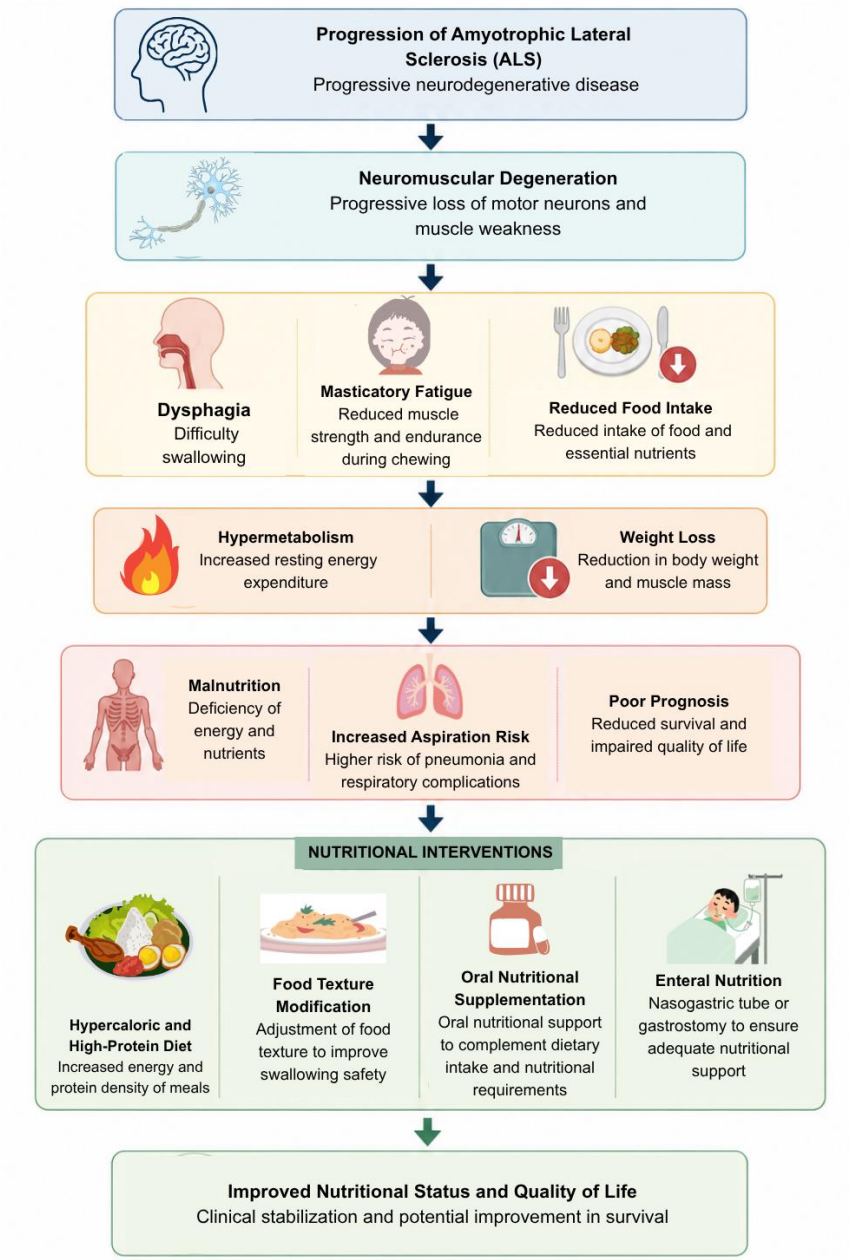
The average survival of patients with ALS ranges from 2 to 5 years after diagnosis (BENTO DCP, et al., 2022). Only 25% of patients survive more than 5 years, and approximately 5–10% survive longer than 10 years. About 10% of ALS cases are familial, while the remaining 90% are sporadic. ALS is considered a multifactorial disease, in which environmental factors, multiple genes, and various pathophysiological processes contribute to disease progression (ABRELA, 2021 and KUBAT GB and PICONE P, 2024).

Treatment of ALS requires a multidisciplinary approach, in which nutrition plays a central role in supporting health and overall well-being. As the disease progresses, patients often develop complications such as dysphagia, loss of appetite, communication difficulties, and feeding problems, which reduce oral food intake and increase the risk of malnutrition and dehydration. To mitigate these effects and improve quality of life, comprehensive nutritional interventions are recommended (SULISTYO A, et al., 2023 and WANG Y, et al., 2021).

Malnutrition and weight loss are associated with a worse prognosis in ALS, demonstrating a negative relationship between decreased Body Mass Index (BMI) and life expectancy. Weight loss is multifactorial and is often related to increased resting energy expenditure and intrinsic hypermetabolism (WANG S, et al., 2022; YANG J, 2019 and ZHU Q, et al., 2023). As the disease progresses, reduced dietary intake further contributes to alterations in body composition and nutritional decline. Therefore, adequate nutritional support is essential to preserve muscle mass, prevent weight loss, and improve patients' quality of life (STEELE CM, et al. 2015).

The nutritional challenges observed in ALS arise from the interaction between metabolic alterations and functional limitations. Factors such as hypermetabolism, dysphagia, and reduced dietary intake act in combination, contributing to progressive weight loss and clinical deterioration. Understanding these relationships is essential to guide effective nutritional strategies and improve patient outcomes. Despite the recognized importance of nutritional intervention, clear and standardized guidelines for ALS management remain limited (**Figure 1**) (MACHADO ENS, et al., 2026). Therefore, this study aims to review the literature on nutritional intervention strategies in ALS, in order to identify effective approaches to prevent malnutrition, minimize weight loss, and improve quality of life and survival.

Figure 1 - Relationship between ALS, Dysphagia, Hypermetabolism, Malnutrition, and Nutritional Intervention Strategies.



Source: Machado ENS, et al., 2026.

LITERATURE REVIEW

The nutritional impairment observed in ALS reflects a complex interaction between metabolic and functional factors that evolve throughout disease progression. Increased resting energy expenditure, frequently associated with hypermetabolism, contributes to elevated energy demands, even in patients with reduced muscle mass. When combined with reduced dietary intake, often resulting from dysphagia and fatigue, this imbalance accelerates the deterioration of nutritional status (MACHADO ENS, et al., 2026).

Malnutrition is therefore a common and clinically significant complication in ALS, directly impacting both quality of life and survival. Weight loss, often caused by a combination of increased resting energy expenditure and reduced energy intake, compromises nutritional status and leads to progressive loss of muscle mass, exacerbating patient frailty and weakness. In addition to affecting skeletal muscle, malnutrition impairs respiratory and immune system function, increasing the risk of infections and respiratory complications. These changes negatively affect prognosis, as malnutrition is associated with clinical deterioration and increased mortality in patients with ALS (GENTON L, et al., 2011 and KURIHARA M, et al., 2021).

Studies indicate a strong association between worsening nutritional status and ALS progression, with malnutrition prevalence ranging from 15% to 55%, considered an important prognostic indicator due to its relationship with reduced survival (ZHU Q, et al., 2023). Weight loss is directly associated with increased mortality risk; each 5% reduction in body weight relative to diagnosis increases this risk by approximately 30%, while a decrease of 1 kg/m² in BMI increases mortality risk by 20%. Additionally, loss of muscle mass is associated with reduced survival regardless of baseline weight, reinforcing the importance of early nutritional intervention. The literature also shows that patients with ALS frequently have insufficient caloric and protein intake, with significant improvement after nutritional counseling. Thus, continuous nutritional follow-up and early interventions are essential to preserve nutritional status, improve quality of life, and prolong survival (ALMEIDA CS, et al., 2016 and TABOR L, et al., 2016).

Weight loss in patients with ALS is multifactorial (ZHU Q, et al., 2023) and may be caused by dysphagia, loss of appetite, emotional problems, inadequate use of non-invasive ventilation, and hypermetabolism (ALMEIDA CS, et al., 2016). The European Academy of Neurology guideline (VAN DP, et al., 2024) recommends that in cases of weight loss or swallowing difficulties, consultation with a dietitian, speech-language pathologist, and/or occupational therapist is essential to guide food composition, consistency, meal frequency, use of nutritional supplements, fluid intake and consistency, choking prevention, appropriate utensil selection, and proper positioning during meals. These interventions are crucial to ensure food safety and improve nutrition in patients with ALS.

Patients with ALS frequently present increased resting energy expenditure, which contributes to weight loss even in individuals with reduced muscle mass (GENTON L, et al., 2011 and KURIHARA M, et al., 2021). Ferri A and Coccurello R (2017) report that hypermetabolism in ALS, characterized by increased energy requirements, occurs even in the presence of malnutrition and muscle loss. This condition may be observed from early stages of the disease and is associated with metabolic alterations such as mitochondrial dysfunction and oxidative stress.

Kurihara M, et al. (2021) describe hypermetabolism as a significant feature in patients with ALS, associated with reduced muscle mass and decreased forced vital capacity. Their findings suggest that increased energy expenditure contributes to the progressive weight loss observed in the disease, even in the presence of reduced physical activity. The authors highlight that monitoring nutritional status and body composition is essential for guiding clinical management and improving prognostic assessment in patients with ALS.

Furthermore, regulation of energy expenditure is complex and involves hypothalamic signaling pathways that affect thermogenesis, glucose metabolism, and lipid metabolism in skeletal muscle, amplifying the impact on nutritional status (DODD GT, et al., 2014 and TODA C, et al., 2013). Thus, weight loss in ALS is not solely due to reduced dietary intake, but also to intrinsic metabolic alterations, reinforcing the importance of nutritional management as a central component of clinical care.

In this context, in addition to hypermetabolism, dysphagia stands out as one of the main factors compromising the nutritional status of patients with ALS. Defined as difficulty swallowing food from the oropharynx to the esophagus (PANEBIANCO M, et al., 2020 and RUGAITIENĖ M, et al., 2022), dysphagia affects approximately 85% of patients with ALS (EPPS D, et al., 2020), impairing food transport from the mouth to the stomach and resulting in serious complications such as malnutrition, dehydration, and aspiration pneumonia, which increase mortality (EPPS D, et al., 2020 and PERRY BJ, et al., 2022).

Typical symptoms of dysphagia include coughing, dyspnea, choking, difficulty initiating swallowing, sialorrhea, nasal regurgitation, vocal changes such as hoarseness, and alterations in eating patterns (RUGAITIENĖ M, et al., 2022). Dysphagia in patients with ALS results from degeneration of upper and lower motor neurons, significantly impairing swallowing. Due to neuromuscular dysfunction, patients often experience fatigue while chewing, leakage of food or liquids from the mouth, prolonged swallowing time, difficulty clearing the oral cavity, and frequent choking episodes. Nasal regurgitation is also common, further increasing the risk of aspiration and related complications (EPPS D, et al., 2020).

As the disease progresses, loss of appetite associated with muscle fatigue that compromises chewing and swallowing further exacerbates these difficulties. This condition results in a marked reduction in caloric and fluid intake, leading to progressive worsening of malnutrition and dehydration. These complications negatively affect patients' quality of life and increase the risk of serious outcomes such as aspiration pneumonia and respiratory failure (MARCHI L, et al., 2024).

Therefore, early and accurate diagnosis, combined with appropriate dysphagia management, can contribute to improved quality of life and help prevent or delay complications (PANEBIANCO M, et al., 2020). Dysphagia assessment is essential in all patients with ALS, both at diagnosis and during regular clinical follow-up. It is recommended that this assessment be performed every three months as part of comprehensive clinical and neurological evaluation (MARIANI L, et al., 2022).

Given that dysphagia compromises intake of essential nutrients due to reduced food consumption, strategies to ensure safe and adequate nutrition are fundamental. Modification of food consistency is an indispensable measure to facilitate swallowing and prevent complications such as aspiration. Diets should include soft, easy-to-swallow foods such as cooked and mashed fruits and vegetables, soft grains, and well-cooked proteins, while hard, crunchy, or difficult-to-chew foods should be avoided to ensure food safety and adequate nutritional intake (VILAR MDC, et al., 2022 and STEELE C M. et al., 2015).

Inadequate nutrient intake due to swallowing difficulties increases the risk of weight loss and changes in body composition, potentially worsening the clinical condition of patients with ALS. Dysphagia management is therefore essential to optimize nutrition and ensure food safety. Among available assessment tools, the Rosenbek Penetration–Aspiration Scale is widely used, as it allows detailed analysis of aspiration risk during swallowing and guides specific interventions to ensure safe and effective intake (PENMAN JP and THOMSON M, 1998).

Additionally, the Dysphagia Outcome Severity Scale (DOSS) is essential for classifying dysphagia severity, facilitating development of individualized treatment plans. These scales are valuable tools for designing appropriate nutritional strategies and monitoring dysphagia progression throughout disease evolution (MOTTA S, et al., 2026; OLIVEIRA MMG. et al., 2008).

Rugaitienė M, et al (2022). emphasize that methods such as Fiberoptic Endoscopic Evaluation of Swallowing (FEES) are essential for determining dysphagia severity and developing an appropriate dietary plan, including adjustments in food and liquid consistency to facilitate swallowing. Treatment often involves dietary modifications, specific swallowing exercises, and use of electrical muscle stimulation to improve swallowing function. The authors highlight the importance of a multidisciplinary approach in dysphagia management, particularly regarding its nutritional implications in patients with ALS.

In clinical practice, these factors rarely occur in isolation. Hypermetabolism increases energy demands, while dysphagia limits intake, creating a negative energy balance that accelerates malnutrition. This imbalance

directly impacts muscle mass, respiratory function, and immune response, reinforcing the importance of early, individualized, and continuous nutritional intervention. Therefore, strategies such as hypercaloric diets, texture modification, and enteral nutrition should be considered complementary approaches rather than isolated interventions (ALMEIDA CS, et al., 2016; PANEBIANCO M, et al., 2020; RUGAITIENĖ M, et al., 2022).

Evidence-based nutritional interventions are crucial to maintain or restore nutritional status in patients with ALS, as malnutrition may accelerate disease progression and reduce survival. Nutritional management strategies include implementation of hypercaloric and high-protein diets aimed at stabilizing body weight and improving quality of life and survival. However, these interventions must be individualized, taking into account the patient's clinical condition and disease progression, reinforcing the need for clear and comprehensive guidelines to optimize nutritional treatment (VILAR MDC, et al., 2022).

In this context, a systematic review with meta-analysis on hypercaloric therapy in patients with ALS highlighted the importance of this intervention. The study demonstrated that hypercaloric diets have shown positive effects on patient survival, preventing muscle atrophy and improving overall prognosis. Analysis of adverse events did not reveal significant differences between hypercaloric therapy and control groups, suggesting that this approach may be considered safe. However, the authors emphasize the need for further research to validate these findings and better elucidate the mechanisms underlying the benefits of hypercaloric therapy in this population (ZHU Q, et al., 2023).

In addition to hypercaloric therapy, adjustment of food consistency is a fundamental intervention as the disease progresses (GENTON L. et al., 2011 and KURIHARA M, et al., 2021). With increasing dysphagia, a pureed diet often becomes necessary for patients who have difficulty chewing and swallowing, minimizing aspiration risk and respiratory complications (STEELE C M, et al. 2015 and SULISTYO A, et al., 2023). Foods with pureed consistency, such as rice, blended beans, purées, porridges, and shredded meat, are recommended due to their ease of swallowing and safety. These adaptations ensure that patients can ingest necessary nutrients without compromising feeding safety (ABRELA, 2021; SULISTYO A, et al., 2023 and WANG TH, et al., 2018).

The use of thickening agents may also be recommended, as they modify the texture of liquids and foods, making them safer for intake. This modification is essential to prevent liquids from entering the airway, thereby reducing aspiration episodes and related complications such as pneumonia. Food consistency should be adjusted to ensure both adequate nutrient and caloric intake and swallowing safety (SCHULZ S, et al., 2022 and WU XS, et al., 2021).

Therefore, nutritional management in patients with ALS must be individualized and adapted to disease progression and patient needs. When applied appropriately and in a timely manner, nutritional strategies have the potential to improve quality of life and prolong survival. Adoption of a multidisciplinary, evidence-based approach supported by clear guidelines is indispensable for successful nutritional management in ALS.

In advanced stages of ALS, when dysphagia is established and oral feeding is no longer recommended, alternative nutrition methods such as Nasogastric Tube (NGT) feeding or Percutaneous Endoscopic Gastrostomy (PEG) become necessary (MARCHI L, et al., 2024 and PERRY BJ, et al., 2022). NGT feeding is indicated for patients who have difficulty ingesting sufficient amounts of food but is recommended only for short periods. PEG is more appropriate for patients with degenerative diseases such as ALS, allowing long-term nutrition that may extend for months or years, providing greater safety and comfort (PANEBIANCO M, et al., 2020).

PEG allows administration of nutrition, fluids, and medications directly into the stomach, which is particularly important for patients with severe dysphagia and aspiration risk. It is considered superior to other methods in terms of complications related to tube insertion and has become the method of choice for nutrition in patients with ALS. The indication for PEG should be discussed in early stages of the disease and revisited regularly as the patient's condition evolves, taking into account swallowing safety and effectiveness (BRAZIL, 2021).

Criteria for PEG indication include nutritional assessment considering significant weight loss (such as a 10% reduction in body weight over the previous three months), presence of moderate dysphagia, and evaluation of respiratory function, particularly Forced Vital Capacity (FVC) around 50% of predicted values. PEG should be considered when one or more of these criteria are present, as FVC measurement is an important indicator for procedural success. Survival also appears to be affected by late PEG indication, especially in patients who have lost more than 5 kg at the time of tube insertion (BRAZIL, 2021).

López-Gómez JJ, et al. (2021) discuss PEG as a nutritional intervention in patients with ALS, showing that early PEG placement is associated with reduced hospitalizations related to procedural complications, although no improvement in patient survival was observed. However, these approaches are not free from complications, including pressure ulcers, esophagitis, aspiration pneumonia, and frequent tube replacement due to dislodgement or occlusion, requiring continuous monitoring and adjustments to minimize risks and improve patient quality of life (MARCHI L, et al., 2024).

Studies show that PEG can prevent weight loss in many patients and even promote weight gain, improving quality of life and survival (BRAZIL, 2021). In a randomized, double-blind, placebo-controlled phase 2 study, hypercaloric enteral nutrition rich in carbohydrates was well tolerated, with fewer adverse events compared to control groups. No participants in the hypercaloric group discontinued the diet due to adverse events, whereas 50% of control participants discontinued for this reason. During five months of follow-up, no deaths occurred in the hypercaloric group, while three deaths occurred in the control group. These findings suggest that hypercaloric enteral nutrition, particularly carbohydrate-rich formulations, may be a safe and potentially beneficial intervention for patients with ALS, contributing to weight maintenance and improved nutritional tolerance; however, further studies are needed (WILLS AM, et al., 2014).

Therefore, selection of alternative nutrition methods such as PEG represents an important measure in dysphagia management for patients with ALS. Early PEG implementation, combined with specific nutritional interventions, contributes to weight stabilization and maintenance of nutritional status, promoting improved quality of life. Although these methods carry risks, appropriate follow-up and continuous adjustment can minimize complications and ensure greater patient safety and comfort, reinforcing the importance of a multidisciplinary approach in ALS treatment.

FINAL CONSIDERATIONS

ALS is a progressive neurodegenerative disease that significantly impairs quality of life, with malnutrition and dysphagia representing major complications associated with weight loss, muscle atrophy, reduced survival, and unfavorable prognosis. Early nutritional intervention is essential to mitigate these effects and improve clinical outcomes. Although nutritional management is recognized as a key component of ALS care, standardized guidelines remain limited. Current evidence highlights the importance of continuous, individualized, and multidisciplinary follow-up to prevent malnutrition, minimize weight loss, and promote overall well-being. Adequate nutrition serves as a fundamental component in disease management, contributing to improved quality of life and potentially prolonged survival. Further research is needed to strengthen the evidence base and support the development of structured protocols for nutritional management in ALS.

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