## Educommunication for food and nutrition in Amyotrophic Lateral Sclerosis

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# Background

As the disease progresses, patients with amyotrophic lateral sclerosis (pwALS) become more dependent on their caregivers, who have a very demanding role and often experience a heavy burden (1). Caregivers are key components of the multidisciplinary team and must receive all kinds of support. Nutritional status is considered an influencing factor in the prognosis of ALS. We have realized the lack of knowledge regarding food and nutrition among caregivers of pwALS in our clinical practice. Nutrition education for these caregivers is essential in improving the nutrition management in pwALS. In this context, educommunication and information and communication technologies (ICTs) are useful strategies for health and nutrition education (2).

### Objectives

To develop educational modules on food and nutrition in ALS, and make them available through a digital platform in a self-instructional format for the general population, especially caregivers of pwALS.

### Methods

ICTs were used to elaborate the modules for online education. First, literature review was carried out on the importance of food and nutrition in ALS. Secondly, a survey was conducted among pwALS, families, and caregivers to gather the main questions and

challenges of patients/family members on this topic, especially concerning the prevention or minimization of malnutrition. Finally, a team of nutrition specialists prepared the educational modules with logistical and technical support from the Laboratory of Technological Innovation in Health (LAIS).

#### Results

Four educational modules were developed regarding 1) Food and Nutrition in ALS; 2) Dietary Modifications in ALS; 3) Tube Feeding in ALS; and 4) Nutrition Tips in ALS. These modules are available at AVASUS, a free online learning platform since June-July 2021. Together, all modules provide 65 hours of course study. In June 2022, more than 9,749 enrollments were registered.

#### Discussion

The use of ICTs made this possible and accessible. We emphasize the importance of health education as a tool for the empowerment of self-care, guiding patients and/or caregivers regarding this disease, and boosting autonomy in decision-making. Technology-led education is an effective way to provide training and refresher courses in a variety of areas, including food and nutrition. This initiative will benefit patients, since maintaining adequate nutritional status is essential for a better quality of life and prolonged survival in pwALS.

#### References

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