PALLIATIVE CARE NETWORK OF WISCONSIN

FAST FACTS AND CONCEPTS #411
NUTRITION FOR PATIENTS WITH AMYOTROPHIC LATERAL SCLEROSIS (ALS)
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Background: This *Fast Fact* discusses nutrition management for patients with ALS, which is a progressive and eventually fatal neurodegenerative disease. Each year, 5000 patients in the United States receive a new diagnosis of ALS (1). Bulbar muscle weakness is a common manifestation and can lead to dysphagia, weight loss, and clinical dilemmas regarding the pursuit of enteral nutrition. *Fast Facts* #73, 299, 300, and 301 provide further information about ALS.

Eating and nutritional issues in ALS: Weight loss from ALS is usually multifactorial, including difficulty self-feeding due to arm weakness, loss of appetite, and hypermetabolism (2). Weight loss and malnutrition are associated with shortened survival times in ALS (2,3). At the first sign of weight loss or dysphagia, patients should be referred to speech language pathologists and nutritionists. These specialists can recommend high-calorie and high-protein nutritional supplements, food and liquid consistency modifications, and safer swallowing techniques (4). Major medical groups recommend that clinicians offer enteral tube feeding as the standard of care in ALS patients who are losing weight (5,6), even though the data on improvement in quality of life and survival are mixed (7,8). While there are no randomized controlled trials comparing survival in those with and without enteral feeding tubes, a Cochrane review described the evidence for a survival benefit as weakly positive (ranging on the order of 3-8 months depending on various clinical factors) (8-10). Since decision-making regarding enteral nutrition is complex and requires careful consideration of a patient's care preferences, involvement of an ALS-specific multidisciplinary clinic is recommended (11,12).

Indications for enteral feeding: Enteral tube feeding should be considered in patients who experience weight loss, significant dysphagia, and significant burden with oral intake (13). Additionally, nutritional supplementation with enteral tube feeding, can be considered for patients who wish to eat for the enjoyment of taste without the burden to meet caloric needs (14).

The effect of respiratory status on decisions regarding nutritional support: Given that forced vital capacity (FVC) may be transiently lower during acute illness, FVC should be routinely measured in the outpatient setting for patients with ALS. In general, feeding tubes should be placed when FVC is greater than 50% since doing so is associated with fewer complications (e.g. hospitalization due to acute respiratory failure) (13). If FVC does fall below 50% prior to feeding tube placement, data and case studies indicate that a feeding tube can still safely be placed with skilled anesthesia support (15).

Nutritional advance care planning (ACP) in patients with ALS: Early consideration of feeding tube placement is crucial as there may come a point in disease progression when the risk of the procedure outweighs the potential benefit. Furthermore, early involvement of patients in ACP helps ensure patient autonomy since worsening dysarthria, dyspnea, or cognitive impairment may limit a patient's ability to participate in later discussions (16). A practical description of the equipment and the post-procedural support required can help patients and families visualize what tube feeding will be like in their homes. Insurers cover most expenses associated with feeding tubes. Patients should understand that they can continue to eat by mouth as able after feeding tube placement and that enteral feeding is not a barrier to hospice enrollment (17,18). For some caregivers, placement of a feeding tube may relieve the stress of slowly feeding the patient several times each day. For others, the care and equipment may be an added burden. A thorough discussion of the potential harms and benefits is recommended (17,19):

- Possible benefits: weight stabilization via improved nutritional intake, reduced nutritional intake time, reliable medication administration, prevention of choking and/or dehydration.
- Possible harms: gastrostomy tube failure, respiratory failure, infection, change in care setting if the patient, caregiver, or facility cannot manage the feeding tube.

What are the procedural options for enteral tube feeding? Two common feeding tube insertion methods include percutaneous endoscopic gastrostomy (PEG) and radiologically inserted gastrostomy (RIG). There is no difference in mortality or peri-procedural complications between these methods (20).

For patients with a FVC less than 50%, RIG may be a better choice as it does not require sedation (21). In general, the largest possible tube diameter is suggested to reduce the risk of tube obstructions (5).

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