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Glossary of ALS-Specific Terms

Term	Abbreviation	Definition
Augmentative and alternative communication	AAC	Communication devices, systems, strategies and tools which supplement or replace spoken language. Examples of AAC include writing boards, eye-gaze technology, and speech-generating devices.
Amyotrophic lateral sclerosis	ALS	Also known as Lou Gehrig's Disease, a motor neuron disease (MND) affecting both upper and lower motor neurons. (See upper/lower motor neuron section.) Life expectancy is on average 2-5 years after diagnosis.
Bulbar		"Bulbar" refers to the "bulb" shaped medulla oblongata. Damage to the 9th-12th cranial (bulbar) nerves in this area causes impairment of chewing, swallowing and speech. Bulbar-onset ALS symptoms start with the facial muscles, speech and swallowing.
Clonus		Uncontrollable jerks of the muscle.
Cough assist machine		Device which helps with ineffective coughing by gradually applying positive pressure to ensure a deep breath, then shifting to negative pressure to assist with pulling secretions upward, simulating a deep, natural cough.
Dysarthria/Anarthria		Dysarthria is difficulty with speech articulation. This can eventually lead to anarthria (loss of speech ability).
Durable medical equipment	DME	Equipment used for medical purposes, including wheelchairs, shower chairs, and feeding tube equipment. DME is provided by DME companies, which process providers' orders and work with insurances to file coverage claims.
Electromyography	EMG	Diagnostic test which measures how well muscles respond to electrical signals emitted by motor neurons.
Eye-gaze technology		Also known as eye tracking or gaze interaction, eye-gaze technology allows users to control a device using their eyes instead of a keyboard or mouse.
Fasciculation		Spontaneous contraction of muscle fibers causing involuntary muscle twitching. Fasciculations are most commonly seen in the arms and legs.
Forced vital capacity	FVC	Part of pulmonary function testing. FVC is the maximum amount of air (in liters) one can forcibly exhale from their lungs after fully inhaling. FVC is typically presented in its percentage predicted value based on sex, age and height. A normal percentage predicted FVC value is 80-120%.
Frontotemporal dementia	FTD	Dementia caused by damage to neurons in the frontal and temporal lobes of the brain. FTD is commonly seen in

		people with C9orf72 gene mutation (form of familial ALS). It is characterized by personality changes, such as loss of empathy, apathy, difficulty using language, impulsivity, and lack of filter.
Intrathecal		Injection (usually by lumbar puncture) into the innermost membrane surrounding the central nervous system.
Motor neuron/motor neuron disease	MND	A neuron (nerve cell) which conveys impulses initiating muscle contraction or glandular secretion. Motor neuron disease (MND) is a group of disorders in which motor neurons in the spinal cord and brain stem deteriorate and die. ALS, PLS and PMA are all MNDs, with ALS being the most common MND.
Negative inspiratory force	NIF	A measurement of respiratory muscle strength assessing how hard a person can inhale through a mouthpiece. A normal NIF value is -100 to -80 cm H2O, and respiratory support (NIV) is indicated for NIF -60 to 0 cm H2O.
Non-invasive ventilation	NIV	Breathing support through a face mask or similar device. Bilevel (BiPAP) machines are the most frequently used NIV. Typically, nocturnal NIV use is prescribed initially before diurnal use as reclined positioning and diaphragm weakness makes breathing at night more difficult.
Primary lateral sclerosis	PLS	A progressive MND in which only the upper motor nerve cells deteriorate. Symptoms include severe stiffness, which can affect the ability to speak, swallow, and walk. PLS progresses more slowly than ALS and is typically not fatal.
Progressive muscular atrophy	PMA	A progressive MND in which only the lower motor neurons deteriorate. Symptoms include muscle weakness and loss of muscle bulk. Life expectancy is 5-10 years after diagnosis.
Pseudobulbar affect	PBA	A condition characterized by episodes of sudden uncontrollable and inappropriate laughing or crying. PBA is often treated with Nuedexta®.
Pulmonary function tests	PFT	Tests measuring lung strength, including NIF and FVC/SVC.
Quality of life	QoL	A multidimensional concept which considers a person's perception of their overall well-being, including their physical, emotional, financial, social, and spiritual health.
Radiographically inserted gastrostomy tube	RIG	Gastrostomy tube inserted percutaneously under fluoroscopic guidance in the interventional radiology department by a radiologist/interventional radiologist. Sometimes known as a percutaneous radiological gastrostomy (PRG).
Sialorrhea		Excessive saliva and drooling due to oral weakness and difficulty swallowing saliva.

Spasticity		Stiff, rigid muscles.
Slow vital capacity	SVC	A measurement of the maximum amount of air that can be exhaled after a full breath in a relaxed manner. A normal SVC value is 70-85 mL/kg. SVC and FVC differ in how air is exhaled during the test. FVC values are typically lower than SVC values as SVC is measured through an unforced maneuver.
Upper and lower motor neurons	UMN/LMN	Nerve cells involved in voluntary movement. Upper motor neurons transmit signals from the brain's cerebral cortex to the brain stem and spinal cord. Signs of upper motor neuron damage include spasticity and clonus. Lower motor neurons transmit signals from the spinal cord to the skeletal muscles. Signs of lower motor neuron damage include muscle weakness, muscle atrophy, cramping and fasciculations.

Introduction

Malnutrition is a common complication and negative prognostic factor of amyotrophic lateral sclerosis (ALS).[1,2,3,4] Many barriers exist to consuming adequate calories, protein, hydration and micronutrients for people with ALS (PALS).[5] The objective of this introductory document is to provide an overview of ALS, review the nutritional implications of ALS, and discuss how RDs can optimize the nutrition status of PALS.

Causes of ALS[6]

Though the full etiology of ALS is unknown, ALS is linked to genetic, environmental exposures, and other potential causes.

- About 10% of ALS cases are genetic (or "familial"). More than a dozen gene mutations have been found to cause familial ALS, with the most common being:
  - SOD1 mutation (12-20% of familial cases)
  - C9orf72 mutation (25-40% of familial cases). This mutation is also linked to frontotemporal dementia (FTD)
- Some environmental factors may increase the risk of ALS, including:
  - Cigarette smoking
  - Exposure to
    - heavy metals (e.g., lead and manganese)
    - pesticides
    - neurotoxins (e.g., cyanobacteria)
    - electromagnetic fields
- Glutamate toxicity
  - Glutamate is a neurotransmitter which carries signals between motor neurons. Some PALS have increased glutamate levels
- Sex
  - Men are at higher risk of developing ALS before age 55 than women
- Military service
  - Military veterans are twice as likely to develop ALS, possibly due to environmental exposure or physical trauma

Diagnostic Process[6]

- ALS diagnosis is established through clinical examinations and a series of diagnostic tests ruling out other potential diseases
  - Diagnostic tests typically include:
    - Brain and spinal cord MRI
    - EMG
  - Diagnostic work up often includes lab work for genetic abnormalities and nutrient deficiencies. Deficiencies in these nutrients may mimic ALS signs and symptoms:

- Thiamine (vitamin B1)
- Cobalamin (vitamin B12)
- Copper

ALSFRS-R[7]

- Disease progression is quantified using a validated tool, the ALS Functional Rating Scale-Revised (ALSFRS-R)
- The ALSFRS-R measures 12 aspects of physical function categorized within 4 functional domains, categorized by color in the chart below: bulbar, fine motor, gross motor, and respiratory
    - Though swallowing is addressed in the bulbar section, the other sections can impact nutrition as well, e.g.,
        - self-feeding and food preparation ability (fine motor)
        - walking (needed for grocery shopping; gross motor)
        - dyspnea and BiPAP use (affects coordination of breath and swallow; respiratory)
- Each aspect of self-reported function is scored from 0 (lowest function) to 4 (highest function), with the total score from all 12 domains ranging from 0 (no function) to 48 (highest function)

Function	Scoring Criteria
1. Speech	4: normal speech process 3: detectable speech disturbances 2: intelligible with repeating 1: speech combined with non-vocal communication 0: loss of useful speech
2. Salivation	4: normal 3: slight but definite excess of saliva in mouth; may have nighttime drooling 2: moderate excessive saliva; may have minimal drooling (during the day) 1: marked excess saliva with some drooling 0: marked drooling; requires constant tissue or handkerchief use
3. Swallowing	4: normal eating habits 3: early eating problems- occasional choking 2: dietary consistency changes 1: needs supplemental tube feeding 0: NPO (exclusive parenteral or enteral feeding)
4. Handwriting	4: normal 3: slow or sloppy, all words are legible 2: not all words are legible 1: able to grip pen, but unable to write 0: unable to grip pen
5. Cutting foods and handling utensils 5a. Without gastrostomy or EN meeting < 50% needs through gastrostomy	4: normal 3: somewhat slow and clumsy, but no help needed 2: can cut most foods (>50%), although slow and clumsy; some help needed 1: food must be cut by someone, but can still feed slowly 0: Needs to be fed

5b. With gastrostomy and EN meeting >50% needs	4: normal 3: clumsy, but able to perform all manipulation independently 2: some help needed with closures and fasteners 1: provides minimal assistance to caregiver 0: unable to perform any aspect of task
6. Dressing and hygiene	4: normal 3: independent and complete self-care with effort or decreased efficiency 2: intermittent assistance or substitute methods 1: needs attendant for self-care 0: total dependence
7. Turning in bed	4: normal 3: somewhat slow and clumsy, but no help needed 2: can turn alone or adjust sheets, but with great difficulty 1: can initiate but not turn or adjust sheets alone 0: helpless
8. Walking	4: normal 3: early ambulation difficulties 2: walks with assistance 1: non-ambulatory functional movement only 0: no purposeful leg movement
9. Climbing stairs	4: normal 3: slow 2: mild unsteadiness or fatigue 1: needs assistance 0: cannot do
10. Dyspnea	4: normal 3: occurs when walking 2: occurs with one or more of the following: eating, bathing, dressing 1: occurs at rest; difficulty breathing when either sitting or lying 0: significant difficulty; considering using mechanical respiratory support
11. Orthopnea	4: normal 3: some difficulty sleeping at night due to shortness of breath. Does not routinely use more than two pillows 2: needs extra pillow in order to sleep (more than two) 1: can only sleep sitting up 0: unable to sleep
12. Respiratory insufficiency	4: normal 3: intermittent use of BiPAP 2: continuous use of BiPAP during the night 1: continuous use of BiPAP during the night and day 0: invasive mechanical ventilation by intubation or tracheostomy

Malnutrition

- Malnutrition is an independent risk factor for reduced survival time[3,4]
  - Malnutrition is difficult to diagnose using typical malnutrition criteria (e.g., Academy/ASPEN consensus statement malnutrition indicators or Global Leadership Initiative on Malnutrition criteria)[5]
  - Inadequate oral intake compounds disease-related muscle mass loss
    - Both the ALS disease process and inadequate oral intake independently lead to muscle mass loss. However, subcutaneous fat loss may be from inadequate oral intake and not from the disease process and therefore, may better reflect response to nutrition intake/intervention[8]
- A "U"-shaped association between body mass index (BMI) and mortality exists[9]
  - Highest survival is seen in the BMI range of 30–35 kg/m^2
  - Decreased survival with BMI > 35 kg/m^2 may be due to weight-induced physical activity burden and respiratory distress

Nutrition Assessment[10]

- A sample ALS medical nutrition therapy note template can be found here
- Approximately 50% of PALS are hypermetabolic, possibly from mitochondrial dysfunction, fasciculations, respiratory demand or other causes
- Mean measured resting energy expenditure has been noted as being 19.7 +/- 6.4% higher than calculated by the Harris Benedict equation (HBE)
- Despite muscle loss with disease progression, 80% of PALS in one study showed no change in metabolic status over time
  - Sustained hypermetabolism may be due to increasing respiratory muscle demands

Nutrient	Calculations[11*]
Calories	• Commonly used weight-based equation: 30-35 kcal/kg/day • Kasarskis equation[12] (incorporates HBE and 6 questions from ALSFRS-R) • Use clinical judgment and adjust estimated calorie requirements as needed based on weight changes, comorbidities, disease stage, fasciculations, etc.
Protein	• Not well studied • Although not well studied, commonly used weight-based equations are 1.0-1.2 gm/kg/day or 1.2-1.5 gm/kg/day • Use clinical judgment and adjust estimated protein requirements as needed based on wound healing, comorbidities, etc.
Fluid	• Not well studied • 1 mL/kcal often used, but one study suggested this equation is inaccurate for use in ALS[13] • Scagnelli equation[13]* • May need additional fluids with sialorrhea

*Click here to access online nutrient need calculation spreadsheet

Diet

- Few studies have investigated the impact of diet quality on ALS disease progression
  - *Anti-inflammatory diet:* One study noted an association between higher intakes of antioxidants and carotenes from vegetables and higher ALSFRS-R score and percentage forced vital capacity (FVC) value[14]
  - *Ketogenic diet:* Data are lacking. A clinical trial of a ketogenic diet was only able to enroll a single patient and lacked a control group.[15] Another trial studying the safety and feasibility of a normocaloric ketogenic diet is ongoing[16]
  - *Gluten-free diet:* Supported by weak data (two association studies and one case report). A population report saw no relationship between celiac disease and ALS[17]
  - *High glycemic load diet:* One observational study found associations between higher glycemic index and higher glycemic load diets and slower disease progression in ALS, suggesting a potential benefit to consuming a high-glycemic diet. Further studies are planned to evaluate this hypothesis as an intervention[18]
- Most studies on the impact of diet quality are observational in nature and limited in number. Until clinical trials are completed and higher quality evidence is available, dietary guidance should focus on a high calorie diet,[19,20,21,22] mechanically altered diet textures (as needed), adequate protein and hydration intake, and energy conservation methods (small, frequent meals; softer textures and smaller bites to decrease chewing effort).

When appropriate, gastrostomy tube placement should be discussed (see "Nutrition Support" section).

Barriers to Adequate Intake

- PALS on average only consume 84% of calorie requirements[23]
- Many barriers exist to consuming adequate calories[5]

Barrier	Cause	Treatment
Hypermetabolism	• Not fully understood	• High calorie foods and oral supplements • G-tube, if appropriate and desired
Dysphagia	• Oral muscle spasticity and flaccid weakness due to degeneration of cortical motor neurons, corticobulbar tracts, and brainstem nuclei	• Mechanically altered diets (per speech language pathologist recommendations) • G-tube, if appropriate and desired
Constipation	• Decreased activity • Diminished diaphragmatic function • Hesitation to move bowels due to ambulatory weakness • Medication side effects • Inadequate fiber intake • Inadequate fluid intake • Altered microbiome	• Increased activity (if able and appropriate) • Bowel medications (stool softeners, laxatives, suppositories) • Increased fiber intake as able (caution if decreased mobility as fiber can worsen constipation) • Increased fluid intake • Role of probiotics being studied

Sialorrhea (excessive saliva)	• Weakened oropharyngeal muscles and subsequent difficulty managing saliva	• Medications: glycopyrrolate, off-label medications (amitriptyline, scopolamine, atropine) • Botulinum toxin injections into the parotid or submandibular gland • Increased hydration
Self-feeding difficulty	• Decreased gross/fine motor skills	• Adaptive feeding equipment (per occupational therapist recommendations) • Finger foods • Caregiver help
Grocery shopping/ cooking difficulty	• Decreased mobility and functionality	• Grocery delivery programs • Meal delivery programs • Prepared meals • Takeout • Caregiver help
Decreased appetite	• Depression • Constipation • Dysphagia and fear of choking	• Address mental health challenges (e.g. need for therapy, support groups, medications) • Address polypharmacy • Treat constipation (see above) • Address dysphagia (see above) • Discuss the role of appetite stimulants and/or G-tube (caution with megestrol in older adults[24])
Fatigue	• Disease progression • Inadequate non-invasive ventilation (NIV) support or compliance	• Address NIV support or compliance • Naps before meals • Small, frequent meals • Softer food textures

Multidisciplinary Team

- Multidisciplinary clinics have been shown to increase median survival rate by 6-10 months[25]
- A multidisciplinary team approach is optimal to identify and address nutrition barriers, with each team member having a unique role[26]

Team Member	Nutrition Barrier	Nutrition-related Role
Registered Dietitian	• Hypermetabolism • Dysphagia	• Conducts nutrition assessments to identify malnutrition and nutrition risk (i.e., nutrition-focused physical examination, diet and weight history, self-feeding ability, food preparation ability, access to food, chewing/swallowing function, appetite, dietary supplement use, and length of time to complete meals) • Calculates nutrition and hydration needs and provides recommendations to meet needs • Suggests dietary alterations to meet recommended texture modifications

		• Inquires about constipation and offers dietary adjustments • When appropriate, introduces the topics of gastrostomy tubes and EN, determines EN regimen, and education on feeding tube care and EN administration
Neurologist, Palliative Care Physician, and Other Providers	• Symptom management (sialorrhea, constipation) • Decision-making	• Order appropriate medications for symptom management • Aid in gastrostomy placement decision-making
Speech Language Pathologist	• Dysphagia • Communication challenges	• Assesses dysphagia and aspiration risk • Suggests diet texture modifications and compensatory swallowing techniques • Provides guidance on communication strategies and devices
Assistive Technology Specialist	• Communication challenges	• Provides guidance on communication devices
Pulmonology and Respiratory Therapist	• Fatigue	• Address respiratory-related fatigue
Occupational Therapist and Physical Therapist	• Difficult self-feeding, preparing meals and grocery shopping	• Teach adaptive techniques for mealtimes and energy conservation
Social worker	• Food insecurity	• Helps procure meals
Mental Health Worker	• Mental health challenges impacting appetite/intake	• Assesses mental health and suggests treatment options

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Nutrition Support

- If in line with goals of care, gastrostomy tubes (G-tubes) and enteral nutrition (EN) are recommended for PALS unable to meet nutrition needs by mouth[27,28]
    - G-tubes are usually placed endoscopically (percutaneous endoscopic gastrostomy; PEG) or radiographically (radiographically inserted gastrostomy; RIG also known as a percutaneous radiological gastrostomy; PRG)
- G-tubes can provide safe and consistent delivery of nutrition, hydration, and medications
- EN often begins as supplemental and is transitioned when needed to meet full nutrition needs as the disease progresses
- Depending on the degree of aspiration risk, pleasure oral feeds may be allowed for quality of life (QoL) purposes
- Observational studies suggest a survival benefit with G-tubes;[29,30] however, randomized control trials comparing the benefits of EN versus continuation of oral feeding are lacking
- Indications for G-tube placement in PALS include:
    - Insufficient nutrition or hydration (evidenced by weight loss, clinical signs, or serum laboratory values)
    - Chewing or swallowing difficulty (food, hydration, and/or medications)
    - Fatigue preventing adequate intake

- Prolonged mealtime (> 45 minutes)
- Some have encouraged pursuit of G-tube placement while forced vital capacity (FVC) is > 50% predicted normal value.[27,31] FVC < 50% has been suggested to increase the risk of respiratory arrest during sedation/anesthesia as well as postoperative ventilator dependence. However, other studies challenge this FVC limit and suggest different risk stratifying tools.[32,33]

- Physical limitations, caregiver availability and patient preferences must be considered when determining EN administration method
- The benefit of G-tubes on QoL in PALS is debatable in the literature[34,35]
  - Individualized approach must be taken when discussing G-tubes
- Low profile/button G-tubes (e.g. MIC-KEY tubes) and G-tubes placed radiographically (RIG) have a balloon internal bumper which requires the tube to be replaced every 3-6 months
  - Replacement/spare can be provided by DME companies
  - Replacement takes ~5 minutes and can be done in the outpatient setting
  - Low profile tube extension sets should be washed after every feeding with warm soapy water and rinsed thoroughly. Sets should be replaced every 1-2 weeks (sets are sent by DME company).

Type of Tube	Description	Picture
Percutaneous endoscopic gastrostomy (PEG)	Has silicone internal (inside the stomach) bumper seen on the far right. Silicone or rubber bumpers can last over a year.	
Radiographically inserted gastostomy (RIG) or replacement tube	Has balloon internal (inside the stomach) bumper seen on the far right. Balloon tubes need to be replaced every 3-6 months. This is also the type of tube used to replace RIG or PEG tubes.	
Low profile (button) tube (MIC-KEY®) with extension	If this tube is desired, it is often not placed until 6 weeks after the first tube is placed. It also has a balloon internal bumper. Balloon tubes need to be replaced every 3-6 months. It requires an extension tube (on right) be connected to use the tube.	

Photo credit: Avanos

- PEG tubes can last multiple years. Routine replacement, if desired, is per surgeon preference. Once the original PEG tube is replaced, it is replaced with a balloon tube, which needs replacement every 3-6 months.
- An informational handout to help PALS with decision-making regarding G-tube can be found here. In addition, the Les Turner ALS Foundation and MND Patient Decision Support website have interactive decision tools for gastrostomy tube placement.

Home Enteral Nutrition

- Home EN via G-tube is common in PALS due to dysphagia and weight loss
- Though the optimal EN formula and administration method for PALS has not been identified, most RDs use fiber-containing, polymeric formulas via syringe/bolus[11]
    - Coram has developed helpful videos (in English) to educate PALS on administering bolus feeds, gravity feeds, and pump-administered feeds
- EN may be initially started to supplement oral intake. As the disease progresses, PALS may later become fully dependent on EN to meet nutrition needs
- Most insurances cover the cost of EN supplies through DME companies
    - ALS diagnosis, regardless of age, qualifies a person for Medicare once they apply for and begin receiving Social Security Disability benefits
    - Details on insurance coverage (including commercial payers, Medicaid and Medicare) and documentation tips for home EN for PALS can be found here
    - A sample EN letter of medical necessity can be found here
    - The cost of groceries to make home blenderized EN is not covered
    - When a patient transitions to hospice, the hospice agency may or may not cover EN supplies. If the hospice agency does, their formulary may be limited, or they may contract with a DME to provide EN supplies
- Guidance to troubleshooting home EN complications can be found here

Refeeding Syndrome

- Refeeding syndrome is a potentially life-threatening nutritional issue characterized by severe electrolyte disturbances and metabolic abnormalities
- Dysphagia, self-feeding difficulty, weight loss, and other factors make people with ALS at risk for refeeding syndrome after feeding tube placement and EN initiation
- Refeeding risk characteristics and consideration to prevent refeeding syndrome in PALS can be found here

Medications

- These are the common medications used in ALS along with their mechanism of action, nutritional side effects, and fasting considerations:[36]

Medication	Mechanism of Action	Potential Nutritional Side Effect	Fasting Considerations
ALS Treatment			
Riluzole (Rilutek®, Tiglutik®, Exservan®)	Glutamate antagonist approved by the FDA in 1995 to extend life by 2-4 months. Available in tablet and suspension form.	Nausea, vomiting, tingling around mouth	Take at least 1 hour before or 2 hours after meals *(taken twice daily, in AM and PM)*
Edaravone (Radicava®)	Free-radical scavenger approved by the FDA in 2017 to help prevent neuronal damage from oxidative stress. Available in intravenous (IV) and oral rehydration solution (ORS) form. Initial treatment cycle: daily dosing for 14 days followed by a 14- day drug-free period. Subsequent treatment cycles: daily dosing for 10 days out of 14-day periods, followed by 14-day drug-free periods.	Swelling of the lips, tongue, face	For ORS form (not IV), don't eat 1 hour after administration. Take on an empty stomach or: - 8 hours after a *high-fat meal* (800-1,000 kcal, 50% fat) - 4 hours after a *low-fat meal* (400-500 kcal, 25% fat) - 2 hours after a *calorie supplement* (250 kcal, e.g., protein drink)[++]
Toferson	Antisense oligonucleotide drug approved by the FDA in 2023 for PALS with SOD-1 mutation. Intrathecal injection administered as 3 initial doses (once every 2 weeks) and then once every 28 days.	Fatigue	None
Pseudobulbar Affect (PBA) Treatment			
Dextromethorphan / Quinidine (Nuedexta®)	Approved by the FDA in 2010 to treat PBA, which is uncontrollable and inappropriate laughter or crying. Recent (to 2024) clinical trials support the idea that Nuedexta can improve bulbar function in PALS, with or without PBA. Comes in capsule form (which can be opened) or compounded into a liquid form.	Vomiting, bloating, diarrhea	None, can take with or without food

Sialorrhea Treatment			
Atropine drops	Tropane alkaloid and anticholinergic	Dry mouth	None, can take with or without food
Hyoscyamine (Levsin®)	Anticholinergic	Dry mouth, constipation	None, can take with or without food
Glycopyrrolate (Robinul®, Dartisla® ODT)	Anticholinergic	Dry mouth, constipation	Robinul: can take with or without food Dartisla: take 1 hour before or 2 hours after meal
Scopolamine transdermal patch	Anticholinergic	Dry mouth, decreased urination (frequency and volume)	None, does not use GI tract
Botox injections to salivary glands	Blocks nerve signals that cause salivary glands to contract	Dry mouth, could migrate and worsen swallowing weakness	No alcohol consumption for 24 hours before or after administration

[++]Expert opinion from this document's authors: continuous/cyclic EN can follow edaravone manufacturer fasting guidelines for "calorie supplement"

Constipation is also very common in PALS. Below are some helpful resources on constipation:

- Patient constipation handout
- Clinician constipation treatment protocol

Dietary Supplements

- Given the lack of treatment options in ALS, many PALS seek alternative therapies such as dietary supplements
- Dietary supplement use is common though may result in drug-nutrient or nutrient-nutrient interactions. Providers and registered dietitians (RDs) should review supplement use routinely to ensure safe consumption
- ALSUntangled is a website created to educate on alternative and off-label treatments advertised for PALS. It reviews many dietary supplements and rates their potential efficacy in ALS
    - In addition, the National Institutes of Health's Office of Dietary Supplements website maintains updated fact sheets on a variety of supplements

We hope you have found this resource helpful in your practice. Please email us at info@alsnutrition.org with any questions or suggested edits.