

amyotrophic lateral sclerosis 🕶

# A guide to nutrition for patients with amyotrophic lateral sclerosis

This guide provides practical advice and information to help you make informed choices about your diet and manage your symptoms effectively

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## Introduction

Amyotrophic Lateral Sclerosis (ALS) is a progressive neurodegenerative disease that affects nerve cells in the brain and spinal cord, leading to muscle weakness and eventual paralysis. Proper nutrition plays a vital role in maintaining your overall health, strength, and quality of life [1].

This comprehensive guide provides practical advice and information to help you make informed choices about your diet and manage your symptoms effectively. We'll delve into the specific nutritional needs of ALS patients, offer practical tips for meal planning, and provide delicious recipe ideas.

By following these guidelines and working closely with your healthcare provider, you can take control of your health and live a fulfilling life with ALS.

## Understanding ALS and its impact on nutrition

ALS can significantly impact your nutritional needs and eating habits [1]. As the disease progresses, muscle weakness can affect your ability to chew, swallow, and even prepare meals [1]. You may experience fatigue, constipation, and a decreased appetite, further complicating your nutritional intake [1]. It's important to understand that people with ALS often have increased energy needs due to the extra effort required for breathing and muscle function.

It is essential to address your nutritional needs proactively. Malnutrition is an independent risk factor for poorer outcomes in ALS, and studies have shown a correlation between malnutrition and a shorter lifespan [2]. Maintaining a healthy weight is crucial, as weight loss can accelerate muscle breakdown and disease progression [4]. Studies have shown that people with ALS who maintain their weight have better outcomes and may even have a longer life expectancy [4].

In addition to the challenges mentioned above, ALS can also affect the gut microbiome, which plays a role in digestion and overall health. Research is ongoing in this area, but it highlights the complex interplay between ALS and nutrition [1].

As ALS progresses, swallowing can become increasingly difficult. While it can be a challenging decision, a feeding tube can help ensure you receive adequate nutrition and hydration when eating by mouth becomes too difficult [4]. Feeding tubes can provide a sense of relief and reduce anxiety around eating and swallowing safely [4].

## General dietary guidelines for people with ALS

A balanced diet is essential for everyone, but it's especially important for people with ALS. Your diet should include a variety of foods from all food groups to ensure you receive the necessary nutrients [6]. Here are some general guidelines:

- Grains: Choose whole-grain bread and cereals with fiber.
- **Vegetables:** Include a variety of colors, especially dark green and orange varieties.
- Fruit: Opt for a variety of colors.
- Dairy: Aim for 3 cups of milk or yogurt each day.
- **Protein:** Choose lean protein sources, such as poultry and fish. Vary your protein intake by including nuts, seeds, beans, and peas.
- Fats/Oils: Prioritize heart-healthy fats like olive, canola, or peanut oils [6].

# Specific nutritional needs for ALS patients

In addition to general dietary guidelines, people with ALS have specific nutritional needs:

- Increased caloric intake: Due to hypermetabolism, where your body burns more calories than usual, you may need to consume more calories than someone without ALS to maintain your weight [7]. A general guideline is to aim for 30-35 kcal/kg/day, but individual needs may be higher or lower [7]. The Kasarskis equation can also be used to estimate your energy requirements [7]. It's important to work with a healthcare professional to determine your specific needs.
- Adequate protein: Protein is essential for maintaining muscle mass and strength, which is especially important for people with ALS. Aim for 1.2-1.5 grams of protein per kilogram of body weight daily [8]. Good sources of protein include eggs, fish, lean meats, poultry, legumes, nuts, and seeds.
- **Sufficient fiber:** ALS can affect digestive function, making fiber intake crucial to prevent constipation. Aim for 25-35 grams of fiber daily through whole grains, vegetables, and fruits [8].
- **Hydration:** Staying hydrated is vital for everyone, but especially for people with ALS, particularly if you have difficulty swallowing. Sip water throughout the day and consume water-rich foods like fruits and vegetables [1].

- **Micronutrients:** Certain vitamins and minerals play a crucial role in managing ALS symptoms and supporting overall health [8].
  - Vitamin D and calcium: Important for maintaining bone density, especially as mobility decreases. Good sources include fortified dairy products, fatty fish, and egg yolks.
  - B vitamins, especially B12: Essential for nerve function and energy metabolism. Found in lean meats, eggs, and fortified cereals.
  - Magnesium: Supports muscle function and may help reduce cramping. Good sources include nuts, seeds, and leafy greens.
  - **Zinc:** Strengthens immune function and supports tissue repair. Found in oysters, beef, and pumpkin seeds.
  - Iron: Crucial for preventing fatigue and supporting oxygen transport.
    Good sources include red meat, beans, and spinach.
  - **Selenium:** Works as an antioxidant to protect motor neurons. Found in Brazil nuts, tuna, and eggs.
  - Vitamin E: Another antioxidant that may help protect motor neurons.
    Found in sunflower seeds, almonds, and avocados.
- Weight management: It is generally recommended that you do not try to lose weight once you are diagnosed with ALS. The goal is to maintain a healthy weight. You may experience minor weight loss due to a reduction in muscle mass. However, dieting is not recommended, even if you feel you are overweight. Interestingly, research has shown an "obesity paradox" in ALS, where a higher BMI may be associated with better survival in some cases [7]. However, it's important to note that obesity can also have potential risks, such as increased physical activity burden and respiratory distress [7].

# Practical advice and meal planning tips for ALS patients

This section provides practical tips to help you manage your nutrition while living with ALS.

#### Meal planning tips

- Eat smaller, more frequent meals throughout the day to avoid fatigue and ensure you're getting enough calories without overfilling your stomach [6].
- Prioritize nutrient-dense foods that provide a high amount of calories and nutrients in smaller portions [8]. Examples include:
  - Avocados
  - Nuts and nut butters
  - Full-fat Greek yogurt
  - Olive oil and other healthy fats
  - Eggs
  - Fatty fish
  - Legumes
  - Quinoa and brown rice
- Adapt food textures as needed to make swallowing easier and safer.
  Choose soft, easy-to-chew foods and avoid those that are hard, sticky, or crumbly [6].
- Create a pleasant and relaxed eating environment to reduce stress and improve your enjoyment of meals [6].

#### Managing swallowing difficulties

Dysphagia, or difficulty swallowing, is a common symptom of ALS. Here are some tips to help you manage it:

- Take small bites and sips.
- Eat slowly and chew thoroughly.
- Concentrate on swallowing.
- Modify food textures. Choose soft, easy-to-chew foods and avoid those that are hard, sticky, or crumbly. You can also use thickening agents to make liquids easier to swallow.
- Sit upright while eating and for at least 30 minutes after meals.
- Consult a speech-language pathologist. They can provide personalized guidance on safe swallowing techniques and recommend appropriate food textures [10].

#### Managing fatigue

Fatigue is another common symptom of ALS that can affect your eating habits. Here are some tips to help you manage fatigue related to eating:

- Take a nap before meals.
- Eat softer foods that require less chewing.
- Consider drinking a nutritional supplement as a meal replacement. [6]
- Try eating 6 small meals per day instead of 3 larger meals.

#### Managing other symptoms

- Constipation: ALS can cause constipation due to decreased activity, medication side effects, and inadequate fiber and fluid intake. To manage constipation:
  - Increase your fiber intake with caution, as too much fiber can worsen constipation in people with decreased mobility.
  - Stay hydrated.
  - Discuss bowel medications with your healthcare professional.
- **Sialorrhea (excessive saliva):** Sialorrhea is caused by weakened oropharyngeal muscles, making it difficult to manage saliva [7]. Treatments include medication or botulinum toxin injections [7].
- **Thickened saliva:** Staying hydrated can help thin saliva [6]. Drinking hot tea with lemon may also help [6]. Limiting very sour or sweet foods can reduce saliva stimulation [6].
- **Depression and decreased appetite:** Depression is common in people with ALS and can affect appetite [7]. Consider seeking counseling, joining support groups, and discussing medication with your healthcare professional [7].

#### Assistive devices

Assistive devices can help you maintain independence and make eating easier:

- Plate guards: Help with scooping food.
- Modified utensils: Easier to grip and manipulate.
- Adaptive cups: Prevent spills.

An occupational therapist can help you find the best assistive devices for your needs [11].

#### Sample meal plan

Here's a sample meal plan for someone with ALS who has no swallowing difficulties:

#### Vegetarian meal plan:

#### **Breakfast:**

- Scrambled tofu with spinach and bell peppers
- Whole-grain toast with avocado spread
- A smoothie with plant-based protein, berries, and almond milk

#### Lunch:

- Lentil soup with a side of whole-grain crackers
- Mixed vegetable salad with olive oil dressing (soft vegetables like avocado, cucumber, and tomatoes)
- Quinoa with roasted sweet potatoes

#### Dinner:

- Grilled vegetable stir-fry with tofu and brown rice
- Soft, baked butternut squash with a side of hummus
- Steamed broccoli with a drizzle of olive oil

#### Snacks:

- Greek yogurt with chia seeds and honey
- Smoothie with spinach, banana, and peanut butter
- Apple slices with almond butter

#### **Non-Vegetarian Meal Plan:**

#### **Breakfast:**

- Scrambled eggs with spinach and feta cheese
- Whole-grain toast with mashed avocado
- A smoothie with protein powder, mixed berries, and almond milk

#### Lunch:

- Chicken salad with mixed greens, avocado, and olive oil dressing
- Soft boiled eggs with a side of whole-grain crackers
- Tuna salad with mashed avocado and cucumber slices

#### Dinner:

- Grilled salmon with mashed sweet potatoes and steamed green beans
- Chicken stir-fry with soft vegetables (e.g., zucchini, bell peppers) and brown rice
- Baked chicken with a side of roasted carrots

#### Snacks:

- Greek yogurt with walnuts and honey
- Smoothie with protein powder, banana, and almond butter
- Hard-boiled eggs with a sprinkle of salt

Remember to adjust this meal plan based on your individual needs and preferences.

# Importance of working with a healthcare professional

It's crucial to work with a healthcare professional, such as a registered dietitian or nutritionist, to develop an individualized nutrition plan. They can assess your specific needs, monitor your progress, and provide ongoing support and guidance [12]. Your healthcare team can also help you address sensitive topics like weight loss, difficulty swallowing, and the use of feeding tubes with empathy and understanding [12].

A registered dietitian can help you:

- Assess your nutritional needs and recommend changes in your diet [13].
- Recommend alternate forms of nutrition, such as tube feeding [13].
- Educate you on the care and administration of tube feeding [13].

## Conclusion

Living with ALS presents unique challenges, but with a proactive approach to nutrition, you can maintain your strength, energy levels, and overall well-being. By following the guidelines and tips in this guide and working closely with your healthcare team, you can make informed choices about your diet and manage your ALS symptoms effectively.

Remember that everyone's experience with ALS is different, and your nutritional needs will change over time. Maintaining open communication with your healthcare team, including your doctor, registered dietitian, and speech-language pathologist, is essential to ensure you're receiving the best possible care and support.

While ALS can affect many aspects of your life, including your diet, there are ways to maintain your quality of life and find enjoyment in food. By focusing on good nutrition, you can support your overall health and well-being as you navigate the challenges of ALS.

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