

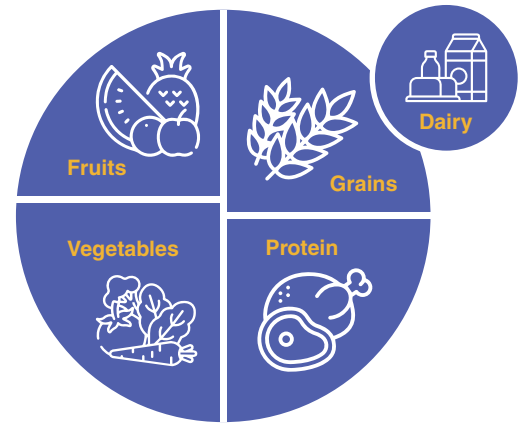





Nutrition with a Neuromuscular Disease



Navigating nutrition with a neuromuscular disease (NMD) requires a thoughtful approach that addresses specific dietary needs and supports overall health and well-being. The right nutrition can play a crucial role in maintaining strength, managing symptoms, and enhancing quality of life. This guide aims to provide strategies for the nutritional needs of individuals with neuromuscular diseases, empowering you to make informed choices about your nutritional needs and preferences.

Basic Guidelines

Try to eat most meals in line with [MyPlate.gov](https://www.myplate.gov).¹ That is ½ the plate being fruits and vegetables, using ¼ of the plate for grains, starches, and starchy vegetables like potatoes and corn, and ¼ of the plate for a lean protein choice. You may want to add a low-fat or fat-free dairy option as well.



	What's Included	What it Provides	What Else to Know
 Grains	Rice, popcorn, breads, pasta, tortillas and cereals made from wheat, barley, buckwheat, quinoa, corn and oats.	Provides calories, protein, dietary fiber, B-vitamins, iron, magnesium and selenium.	Make at least half of your grains whole grains. Whole grains are a good source of fiber. Fiber plays a large role in bowel health and regularity.
 Proteins	Meat, poultry, fish, beans, lentils, eggs, peas, nuts, seeds and soy products	Provides protein, B-vitamins, Vitamin E, iron, zinc, and magnesium. Also provides amino acids required for production of hormones, red blood cells, neurotransmitters and energy, wound healing, and tissue.	Make sure to include lean meats. It is important to eat protein throughout the day to ensure availability when needed.
 Dairy	Milk, lactose free milk, yogurt and cheese and fortified soy milk	Provides protein, calcium, phosphorous, Vitamins A and D, B12, riboflavin, potassium, zinc, choline, magnesium and selenium. When mobility is decreased, bones may weaken, increasing the possibility of a long bone fracture. Adequate calcium and Vitamin D can help to prevent this.	Does not include sour cream, cream cheese, cream, and butter.

	What's Included	What it Provides	What Else to Know
 <p>Fruits</p>	This includes all fruits and 100% fruit juice. Fruits may be fresh, frozen, canned, or dried/dehydrated. Fruits can be eaten whole, cut up, puréed (mashed) or cooked.	<p>Provide essential nutrients like Vitamin C, folate, potassium, and fiber.</p> <p>Fruits are low in sodium, calories, and fat.</p>	Focus on whole fruits instead of fruit juice.
 <p>Vegetables</p>	Includes all non-starchy vegetables. Vegetables may be raw or cooked and can be fresh, frozen, canned, or dried. They can be whole, cut-up, or puréed (mashed).	Provide a good source of Vitamin C, Vitamin A, folate, potassium and fiber.	Vegetables are organized into 5 subgroups based on their nutrients: dark green; red and orange; beans, peas, and lentils; starchy; and other vegetables.

Fruits and vegetables provide fiber and antioxidants and are key in an anti-inflammatory diet. Their fiber and water content contribute to satiety when controlling weight gain. Fruits and vegetables are also a good source of potassium. When on steroids it is important to increase the intake of potassium rich foods. They are also an excellent low-calorie snack and source of hydration.

Specific Considerations for Individuals Living with a Neuromuscular Disease

Constipation

Constipation is a common problem across most NMD. This can be related to inadequate fluid and fiber intake, lack of activity and poor muscle strength.

Fluid Intake

People living with NMDs very often limit their fluid intake. This may be done to limit trips to the toilet or because they cannot drink on their own. This lack of fluid may result in constipation and/or a urinary tract infection (UTI). Discuss your specific fluid needs with your dietitian. Fluids can come from water, milk, juice, broths, Jello, other low sugar beverages and fruit. Strive for water to be your drink of choice, but other calorie-free options are fine as well. Adequate fluid intake is recommended to help with constipation, heart function, thinning of mucus to help prevent upper respiratory infections and to help prevent UTIs.

Anti-Inflammatory Diet

This may be useful in conditions like myasthenia gravis or other auto immune disorders. An anti-inflammatory diet should include foods high in:

- Omega-3 fatty acids like walnuts, ground flaxseed, flax seed oil, dark green vegetables, salmon, sardines.
- Red, yellow, orange vegetables, dark green leafy vegetables, green and black tea, citrus fruits, other vegetables, whole grain breads and cereal²
- Spices and herbs like turmeric, curry powder, ginger, garlic, cinnamon, thyme, rosemary.
- Avoid refined and processed carbohydrates.

Specific Considerations for Individuals Living with a Neuromuscular Disease (cont...)

Fiber Intake

Fiber comes from fruits, vegetables, beans, nuts, seeds, and whole grains. If consuming adequate dietary fiber is challenging, fiber supplements can help meet this need.

Probiotics

A probiotic supplement can help to improve bowel health and may play a role in correcting constipation and as an anti-inflammatory agent.

Healthy Weight

Achieving a healthy weight is one of the main areas of concern. Healthy weight means the body size that helps you with mobility, immunity, recovery from illness and prevention of skin breakdown. Whether one is trying to gain, lose, or maintain their weight, is a matter of energy balance. That is, the calories consumed as food and drink versus the calories expended through metabolic and physical activity.



Sugar Intake

Sugar should be limited, or in moderation, to control weight gain, dental health, and diabetes.

Salt Intake

Salt should be limited when on steroids and in the management of hypertension.

Supplements

Some supplements have adequate evidence to be considered as useful. Please check with your doctor before taking any supplements.

- Multivitamin – Especially if there is decreased or restricted intake of foods and beverages.
- Calcium and Vitamin D – People with NMDs are susceptible to long bone fractures.
- Creatine monohydrate (CrM) (**NOT recommended for children less than 18 years of age**) – improved strength and exercise performance. Please check with your doctor before use.
- B6, B12, & Folate – Cellular metabolism, prevents some anemias.
- Fish oil – Anti-inflammatory, may slow/reverse neuropathy.
- Turmeric – Anti-inflammatory

Challenges and Solutions



Fatigue

Challenge

Fatigue is a common problem in NMDs and affects virtually every aspect of one's life, but it certainly affects one's nutritional status. Fatigue will prevent you from preparing your meals and make you stop eating before you are finished because you are tired. The muscles in the throat can be fatigued making it more difficult to meet your nutritional requirements.

Possible Solutions

Move your largest meal to an earlier time so it occurs before you have been talking and swallowing all day and you are more tired. You may also want to cook in larger quantities and store or freeze food for later.



Fasting

Challenge

Avoiding fasting in NMD is essential to prevent hypoglycemia (low blood sugar), ketoacidosis (a metabolic state that occurs when the body produces too many ketones, which are chemicals that build up in the blood and urine) and muscle breakdown. You are at greater risk for this when you are sick.

Possible Solutions

It is suggested that people with NMD fast no longer than 6-8 hours. To do this eat meals at regular intervals, eat a bedtime snack and breakfast soon after you wake up in the morning. When sick, make sure to drink some orange or apple juice to reduce the risk of low blood glucose.



Decreased muscular function

Challenge

May prohibit you from preparing a meal, using utensils, lifting food to your mouth, or safely chewing and swallowing the bite.

Possible Solutions

Talk to your therapist or physician about adaptive equipment. Choose prechopped vegetables, frozen and convenience foods, slow cooker foods, and sheet pan meals. Consider meal delivery services.



Swallowing

Challenge

When living with a NMD, many aspects of life become more challenging, including the act of eating and/or feeding oneself. When swallowing is difficult or impossible, it is called "dysphagia" and presents danger in the form of choking and/or aspiration pneumonia.

Possible Solutions

When dysphagia is present, it may be recommended to choose foods that are easier to chew and swallow. This may mean choosing softer or ground or chopped foods like meatloaf or other ground meats with sauce, fish, mashed potatoes, macaroni and cheese, or oatmeal. In some cases, it may be necessary to modify the texture of foods. They may be mechanically chopped, ground, or pureed depending on the severity of swallowing deficits. Liquids may also be thickened, if necessary. This slows down the process of swallowing to make it safer. Most any liquid can be thickened using a product like Thick-It® or Thick & Easy® which can be purchased at most pharmacies.

Covering Costs

Check your insurance policy to see if it will cover your visit with a Registered Dietitian Nutritionist (RDN). Most private payers (eg. BCBS, UHM, Aetna, etc.) cover RDN visits, but it is highly dependent on the specific policy, so it is important to check with the insurer. Medicare Part B only covers RDN visits in cases of diabetes, chronic kidney disease, and for those who have had a kidney transplant within the last 3 years.

If one has a feeding tube, Medicare will cover the formula 100% if it represents 100% of your nutrition. This is under Medicare Part A for inpatient and skilled nursing settings. When feedings are done at home, it falls under Medicare Part B. Private payers typically do not cover feeding tube formula in any instance.

Special Considerations

For Feeding Tubes

When one is unable to safely consume enough food, it may be required that you get a feeding tube. This is a tube inserted directly into the stomach from outside the body. It is important to note that having a feeding tube does not prevent you from eating orally. To the extent that it is safe to do so, one may choose to receive the bulk or all nutritional requirements through formula, but then eat for pleasure. This removes the pressure to consume an entire day's worth of nutrition orally while still allowing you the pleasure of your favorite foods. The use of a feeding tube may also drastically reduce the time it takes to eat a meal and reduce the energy used to do so. There are many formulas that may be recommended including some that consider comorbidities like renal disease or diabetes as well as some made from blended foods. Discuss with your Registered Dietitian Nutritionist (RDN) what may be best for you.

For Children with Neuromuscular Disease

In addition to managing the chronic disease you have to ensure adequate nutrient intake for brain growth, bone growth and meeting needs during the different stages of development from infancy to puberty to adulthood.

Measuring height and weight for someone who is unable to stand is a challenge so alternate height measurements are often used along with skinfold measurements to assess if you are at a healthy nutritional status.

For ALS

In ALS, it is generally recommended to maintain your weight and to try not to lose weight. This can be challenging in that the disease increases the number of calories needed and makes it more difficult to safely consume enough energy. To combat this, you may be told to eat ice cream or to add fats to your foods. This is because fat has more than twice the calories of carbohydrates or protein by weight making it more efficient and easier to consume adequate calories to maintain weight.

Strategies for increasing caloric intake:

- High calorie food choices
- Adding high calorie condiments and toppings like gravies, sauces, creams, and dressings to foods.
- Calorie boosters like Benecalorie® may be added to foods.
- Oral supplements like Boost®, Ensure®, Glucerna®, Pediasure®, Boost® Kid Essentials™ and Kate Farms® can provide considerable calories in a fairly small volume.

Strategies for controlling weight gain:

- Choose smaller portions
- Limit intake of sugary foods and beverages.
- Avoid processed snacks and convenience foods.
- Avoid fried foods.
- Choose smaller portions.
- Calorie counting using a smartphone app

Resources

¹Learn how to eat healthy with myplate. MyPlate. (n.d.). <https://www.myplate.gov/>

² Scheiber, A. (2023, October 28). Anti-inflammatory diets. StatPearls [Internet]. <https://www.ncbi.nlm.nih.gov/books/NBK597377/>

About Muscular Dystrophy Association

Muscular Dystrophy Association (MDA) is the #1 voluntary health organization in the United States for people living with muscular dystrophy, ALS, and related neuromuscular diseases. For over 70 years, MDA has led the way in accelerating research, advancing care, and advocating for the support of our families. MDA's mission is to empower the people we serve to live longer, more independent lives.

To learn more, please contact the MDA Resource Center at 1-833-ASK-MDA1 or email ResourceCenter@mdausa.org.

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DISCLAIMER: This document is meant to inform and educate the community. The information presented is not intended to replace discussions with your healthcare provider and is not and should not be considered to be medical advice. Please consult with your healthcare team for information specific to you.