

Nutrition Guide for People Living with Myotonic Dystrophy



The Myotonic Dystrophy Foundation is the world's largest myotonic dystrophy-only patient advocacy organization. Our programs include funding critical research, providing comprehensive resources and support to affected individuals, advocating with government agencies to enhance the drug development pipeline, increase research funding, and improve patient services.

Disclaimer: This guide was created to help educate you about nutrition. This guide does not replace any advice from your doctor or dietitian and is meant to be educational only. Always consult your doctor or dietitian before making any significant changes to your diet.

A publication of the Myotonic Dystrophy Foundation (MDF)

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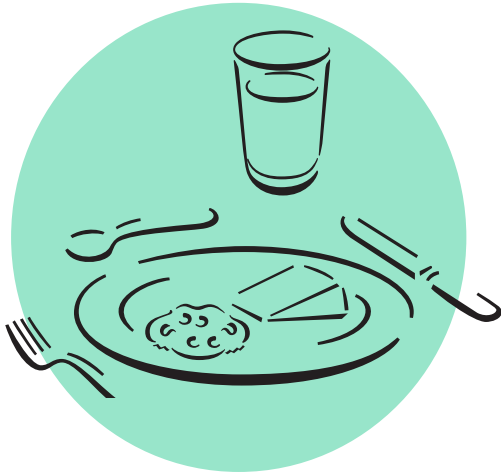
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Basics for a Healthy Diet

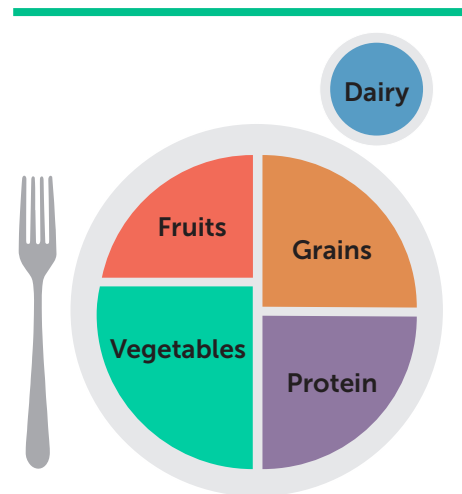
It is important to have a basic understanding of nutrition before you read this entire guide. Nutrition is the process of providing or obtaining the fuel necessary for health and growth.

- Calories are units of energy used in nutrition. Calories provide nourishment for our bodies and come from three primary macronutrients: protein, fat, and carbohydrates. Recommended sources:
 - Protein: Beans, lentils, meat/poultry, eggs, seafood, nuts, seeds, dairy, soy, tofu
 - Carbohydrates: Fruits, starchy vegetables (corn, potatoes, peas, and lentils), grains (oats, quinoa, corn, rice, rye, barley), dairy
 - Fats: Oils (canola, olive), nuts, seeds, avocado, cold water fish
- How many calories are needed? *Enough for a child to grow and for an adult to maintain, gain or lose depending on their needs.*
- Eating a variety of fruits and vegetables and limiting sweets and sweetened beverages is important.
- Poor nutrition can cause low energy. Consider the common saying, “*you are what you eat*” when assessing your energy level.

Getting Started on a Healthy Diet

Here are some strategies and tips to consider when you first begin a healthy diet.

- **Increase fruits and vegetables**, strive for a “rainbow of colors” on your plate - Low calorie, high nutrient and fiber content, helps with constipation and weight management.
- **Eat lean meat, fish and poultry** - Grilled, baked or broiled.
- **Drink enough fluids** - Water helps maintain weight and can help prevent and relieve constipation.
- **Increase your intake of whole grains.**
- **Incorporate beans and legumes** into your meals at least 3 times per week - Provides protein, fiber, and B vitamins.
- **Decrease sugary drinks, juice and desserts** - This will help with weight management.
- **Decrease caffeine intake** - This can decrease side effects like fast heart rate, muscle tremors, upset stomach and increased urination.



Check out [choosemyplate.gov](https://www.choosemyplate.gov) for an easy-to-follow plan for healthy eating and more.

The MyPlate model shows the five food groups (fruits, vegetables, proteins, grains, and dairy) in a place setting. It is designed to help you understand what types of food to include in each meal.

Diet and Myotonic Dystrophy

Research has not shown that any specific diet is helpful to decrease symptoms of myotonic dystrophy (DM). Nutrition recommendations for DM are similar to the rest of the population. The following are some general guidelines that can be helpful.

- Eat a well-balanced diet. Avoid cutting out specific food groups from your diet unless needed for therapeutic reasons (for example, celiac disease, etc.).
- Don't skip meals. Your muscles need a steady dose of energy to function.
- If you are tired and can't fix foods easily, consider easy foods or drinks that take less effort to fix and eat.
- If you have trouble swallowing, work with a speech therapist and dietitian to find the best foods that you can tolerate safely.
- Try to maintain your weight. It is hard on your body when you gain or lose weight frequently.
- Take a daily multivitamin.
- If you are taking steroids, also ensure you take calcium and vitamin D as steroids can cause a deficiency of these vitamins and minerals.
- Spread out meals/snacks. Your body and muscles need constant energy spread throughout the day.
- Drink at least 6-8 glasses of water per day. Dehydration makes us more tired and weak.
- Remember, more protein does not equal more muscle. While protein is used to maintain tissues and muscle, too much protein may cause you to lose calcium. A balanced diet will give you adequate protein to prevent muscle breakdown. Divide protein containing foods throughout the day.



Sample Mini-Meals and Snack List

A good mini-meal has one item from each section:

Protein/Fat

- Tuna pouch
- Hard-boiled egg
- Prepackaged nuts/seeds
- Nut Butter
- Hummus
- Greek yogurt/milk

Carbohydrate

- Whole grain pita bread/crackers
- Fruit
- Carrots
- Peapods
- Cereal

Managing Constipation with Myotonic Dystrophy

DM causes decreased muscle mass and function; since your gastrointestinal tract is a muscle, this may result in constipation. The following are some tips to help with this issue.

- **FACT:** Food can help with constipation!
- Eat 3-5 servings of fresh fruits and vegetables daily. Try to choose fruit over juices. A serving size is 1 piece of fruit or vegetable or 1/2 cup of canned, fresh, or frozen.
- Increase fiber slowly. If you start eating too much fiber at once, it can make you feel worse. Fiber is found in the following foods:
 - Fruits, vegetables, beans, whole grain cereals, whole grain bread, oatmeal, nuts.
- How much fiber should you consume? The easy answer is more than currently consumed and increase slowly.
- **Adults:** 25-35 grams per day
 - **Children:**
 - 1-3 years old - 19 grams per day
 - 4-8 years old - 25 grams per day
 - 9-13 years old - 25-30 grams per day
 - 14-18 years old - 25-38 grams per day
- Check food labels, foods with 3-5 grams or greater of fiber per serving are good.
- Drink plenty of liquids - increasing fiber without increasing fluids can make your constipation worse.
 - **Fluid recommendations for children:** (*all are 8-ounce glasses)
 - 5-8 years old - 5 glasses per day
 - 9-12 years old - 7 glasses per day
 - **Fluid recommendations for those 13 years and up:**
 - At least 8 to 10 glasses per day
- Prunes and prune juice help relieve constipation.
- Probiotics (live and active cultures) such as yogurt, kefir, and supplements can help.
- After increasing fiber and fluids, you may still need help. Many people need medication as well as diet changes to help with their constipation. Stool softeners such as Colace and Senokot and are often used. Ask your doctor or dietitian for guidance on this.



Popular favorite: Prune juice

Being Overweight with Myotonic Dystrophy

Maintaining a healthy weight can be difficult since myotonic dystrophy can affect exercise and the ability to move around. Here are some tips and ideas to help.

- Watch portion sizes. If you can't exercise much, you will need fewer calories.
- Considerations:
 - Less mobile and less active individuals usually require fewer calories.
 - Fewer calories per pound of body weight are usually required with age.
 - Decreased lean muscle mass usually requires fewer calories.
- Don't drink liquids that have calories. This is an easy way to consume too many calories.
 - What do I drink instead of soda, juice and artificially sweetened beverages? Water, seltzer water, sugar-free lemonade, unsweetened tea.
 - Do I need sports drinks? No.



- Don't skip meals. When you skip meals, you may overeat at the next meal.
- Eat meals at the table and avoid using screens during meals. It is easier to eat more if you are not paying attention to what you are eating.
- Keep your hands and mouth busy. Chew gum or sugar free candy.
- Brush your teeth so you don't feel like eating more food.
- Try to limit eating out to fewer than 1-2 times per week. You can usually control what you eat better at home.
- Use smaller plates and bowls to feel like you are eating more.
- Pause before having another serving of food. It takes your brain 20 minutes after eating to tell you that you are full.
- Eat slowly and chew your food thoroughly.
- Try to include fat and protein with meals and snacks to help you feel full longer.
- Eat more low calorie fruits and vegetables. Have them cut up and in the refrigerator so they are ready to eat.
- **FACT:** Large meals increase heartburn. Limit eating to one hour before sleeping, limit spicy food, consider smaller, more frequent meals.



Popular easy-to-prepare favorite: Birds Eye Frozen Steamfresh Protein Blend

Being Underweight with Myotonic Dystrophy

It can be hard for some people to gain weight with DM due to digestion and swallowing issues. Here are some tips and ideas to help.

- Eat snacks between meals. If you get full quickly, have 6 smaller meals so you don't get full as quickly.
- Try to replace water with other liquids that have calories, such as milk and smoothies.
- Try milkshakes and other nutrition supplements. Liquids are easy to drink and take less effort to drink and prepare.
- Add condiments to food, such as salad dressing, sauces and gravies, guacamole, and hummus to make it easier to swallow and add calories if needed.
- Make the foods you eat count. Eat higher calorie foods instead of filling up on low calorie foods.
- Eat canned fruits in heavy syrup for more calories or dip your fruit in yogurt, peanut butter or other high calorie sauces/dips.
- Add higher fat foods to the food you eat (butter, healthy oils, avocado, nut butters).
- Add ice cream to nutritional supplements such as Boost and Ensure to make them taste good and increase calories.



Popular favorite: Try Carnation Breakfast Essentials

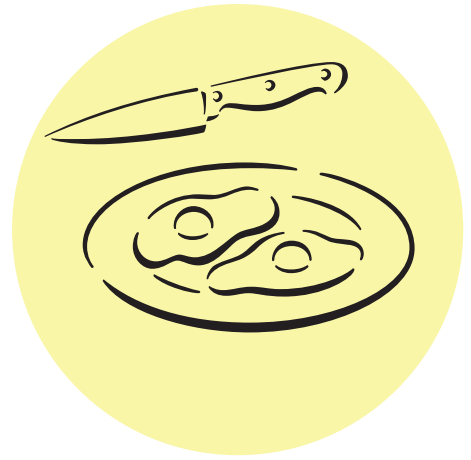


Managing Swallowing Problems (Dysphagia) with Myotonic Dystrophy

Since our throat is made up of muscles, swallowing can be affected for individuals with myotonic dystrophy. Many individuals with DM complain of a feeling of food "sticking" in their throat. Weakness in facial muscles can lead to problems biting, chewing and swallowing.

- Eat foods that are softer and easier to chew such as chicken salad, ham salad, egg salad, tuna salad, grits, polenta, orzo, applesauce, watermelon, soft mashed fruits and vegetables such as bananas, berries, sweet potatoes, spaghetti, squash, or smoothies.
- Smoothies...
 - Are a great way to get protein, fruits, vegetables, fiber and dairy all in one drink, but they can be high in calories.
 - You should not drink smoothies in addition to a meal unless you are having trouble gaining weight or getting enough protein.
 - For commercial smoothie products, look for options that are high in protein but lower in calories.
 - For homemade smoothies, be careful what sweeteners you use. Fresh fruit is healthy but combined with yogurt, juice and honey it packs a lot of calories.

- Try not to eliminate food groups. Think creatively and modify food and beverage textures and consistencies.
- Add sauces and gravies to food to help with food not sticking in your throat.
- Cut up food into smaller bites.
- Eat slower and chew more.
- Alternate liquids and solids to help with swallowing.
- Use adaptive utensils or plasticware, straw cups or camelbacks.
- See a speech therapist if you have any questions or concerns about your swallowing.
- When possible, try not to eat alone.
- During mealtime, focus only on eating and avoid using technology and devices.



 **Popular favorite: Try Smuckers Uncrustables**

Modified Foods

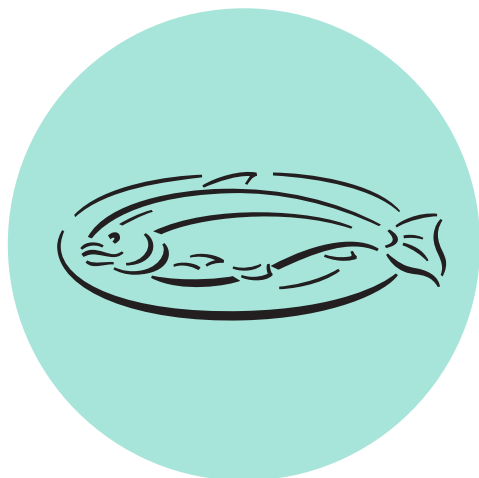
Some people with myotonic dystrophy will benefit from eating modified foods, meaning foods that are moistened, peeled, cooked, chopped, and pureed, so they are easier to eat. Below is a chart of the major food groups with examples of modified foods.

Food Group	Level 1 (Soft)	Level 2 (Minced and Moist)	Level 3 (Smooth Puree)
Grains	Moistened bread, cooked/cold cereal, rice	Moistened pancakes, noodles, mashed potatoes	Pureed starches, breads
Fruits	Soft peeled fresh fruits, soft berries	Canned, cooked fruits - no skin, juice some pulp	Pureed fruits, juice, no chunks, smoothies
Vegetables	Cooked tender vegetables, shredded lettuce	Soft, well cooked vegetables, chopped or diced, salsa	Pureed vegetables, tomato sauce, no chunks
Dairy	Milk, yogurt, cottage cheese, cheese	Milk, soft yogurt, cottage cheese	Milk, buttermilk smooth yogurt
Protein	Thin sliced, ground tender meat, eggs	Moistened ground or cooked meat, tuna, casserole, beans, scrambled eggs	Hummus, soft tofu with liquid, pureed meat
Desserts	Easy to chew, tender cakes and cookies	Pudding, soft fruit pies, moistened cakes, seedless jams	Smooth pudding, shakes, ice cream,
Fats	Smooth, creamy fats	Butter, oils, cream sauces and gravy, sour cream, whipped topping	Butter, oils, smooth sauces and gravy, sour cream, whipped topping

Feeding Tubes

For children and adults who are unable to take enough nutrients by mouth safely, a feeding tube may be recommended. Here is some basic information about feeding tubes; speak with your doctor if you think a feeding tube is appropriate for you.

- A feeding tube can provide support in the short term or the long term.
- As long as there is no aspiration present, eating by mouth can continue.
- Nasogastric tubes (a flexible tube of rubber or plastic that is passed through the nose, down through the esophagus, and into the stomach) are considered a short term method to provide nutrition.
- Gastronomy tubes (a tube inserted through the abdomen that delivers nutrition directly to the stomach) are a longer term method to provide support.
- When to consider a feeding tube:
 - Failed swallow study
 - Growth failure/losing weight
 - Increasing calories is not working
 - Issues with chewing/swallowing
 - Fatigue with feeding
 - Hydration concerns
- Formula type depends on individual tolerance/nutrition needs; formula types include standard, soy, blenderized, hydrolyzed, and elemental.
- Insurance coverage for formula varies, check with your provider before ordering formula.
- Consider a feeding tube before it becomes an emergency!



Supplements

For some individuals with DM, supplements can be important to nutrient intake but discuss supplement use with your doctor **BEFORE** starting. We will only recommend supplements that have been clinically proven to help DM symptoms, but at this time, there are none.

- Consider a daily multivitamin.
- If you are not eating fish two times per week, consider fish oil as a source of omega-3 fatty acids (check for mercury free).
- Take Vitamin D and Calcium supplements if you are deficient.
- Use caution with supplements! Supplements do not need to follow the same guidelines or standards as food/drugs. Check the Office of Dietary Supplements for guidance: <https://ods.od.nih.gov/>

Where to Get Answers

Do you have further questions about managing diet and nutrition with DM? Consider the below.

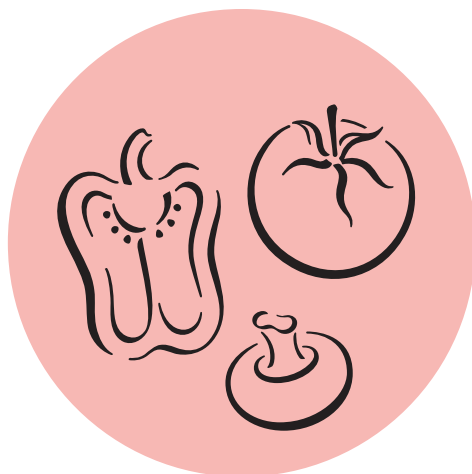
Get help from a Registered Dietitian (RD) or Registered Dietitian Nutritionist (RDN):

- RD = Registered Dietitian/Nutritionist. RDs have a degree in nutrition and have completed an approved internship.
- LDN = Licensed Dietitian/Nutritionist. LDN means RD is licensed in the state where they practice.
- All hospitals hire RDNs.
- Consider dietary evaluation every 1-2 years for adults, 3-6 months for children, or if you are having trouble gaining weight or using a feeding tube.



Consider a Speech Language Pathologist (SLP) or Occupational Therapist (OT) for:

- Assessing for swallowing issues
- Improving oral motor skills, feeding therapy
- Working on fine motor/hand skills
- Altering texture of foods (adding thickeners, puree) to decrease energy spent on eating
- Positioning
- Adaptive equipment

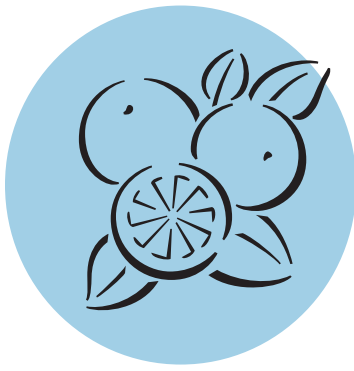


If you want to know exactly how your eating measures up:

- Consider a 3 day food record with analysis from a dietitian.
- Track yourself online at <https://cronometer.com/>
- Use an app such as My Fitness Pal, Loselt!, MyNetDiary.

Reliable nutrition information:

- Contact the Academy for Nutrition and Dietetics for an RDN near you. <https://www.eatright.org/>
- Visit the US Department of Agriculture website for food and nutrition information and programs. <https://www.usda.gov/topics/food-and-nutrition>
- Contact us for further assistance. <https://www.myotonic.org/>



Reference List:

Nutrition Issues Related to Myotonic Dystrophy

<https://www.myotonic.org/digital-academy/nutrition-issues-related-dm>

In this webinar, Kari Lane, RD, CNSC, Clinical Dietitian at the University of Utah, discusses nutritious diets to maintain heart and gastrointestinal health for people living with myotonic dystrophy.

Nutrition and Myotonic Dystrophy

<https://www.myotonic.org/sites/default/files/pages/files/Meyers-Nutrition-2019.pdf>

<https://www.myotonic.org/digital-academy/exercise-nutrition-speech-2019-myotonic-annual-conference>

In these presentations from the 2019 MDF Annual Conference, Robin Meyers, RD, MPH, LDN from the University of Pennsylvania reviews current strategies for managing DM symptoms, research and nutrition.

Nutrition and Myotonic Dystrophy

<https://www.youtube.com/watch?v=i1OUQLwmUNk&feature=youtu.be>

In this support group webinar, Susan Whitacre, MS, RD, LD, Clinical Dietitian at the MDA Clinic at the University of Kansas Medical Center, discusses diets that are best for DM, managing constipation, dietary considerations for those who are underweight and overweight, swallowing issues and more.

Debunking Myths and Eating Strategies

<https://www.myotonic.org/sites/default/files/MDFNutrition08292017.pdf>

Presented by Rebecca Hurst Davis, MS, RD, CSP, CD, CNSC, Clinical Dietitian at Intermountain Homecare and Hospice/Primary Children's Hospital Salt Lake City, UT. This presentation from the 2017 MDF Annual Conference reviews general healthy nutrition guidelines and strategies, feeding tubes, referrals and common questions.

Food Preparation for the Myotonic Dystrophy Community

<https://www.myotonic.org/digital-academy/food-preparation-dm-community>

This webinar covers a basic understanding of adult nutrition, dysphagia (swallowing difficulties), and food preparation. Dr. Krongold (adult-onset DM1) and her partner Jessica, demonstrate the tools needed to prepare three simple, nutritious meals for people with chewing and/or swallowing difficulties.

The mission of the Myotonic Dystrophy Foundation is to enhance the quality of life of people living with myotonic dystrophy and accelerate research focused on treatments and a cure.



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