

Duchenne muscular dystrophy ▾

A guide to nutrition for patients with Duchenne muscular dystrophy

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

Duchenne muscular dystrophy (DMD) is a progressive muscle-wasting disorder that significantly impacts a person's quality of life. While there's no cure, a well-balanced diet can play a crucial role in managing symptoms, maintaining muscle mass, and supporting overall health.

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 individuals with DMD, offer practical tips for meal planning, and provide strategies for adapting to changing dietary needs as the condition progresses.

By following these guidelines and working closely with your healthcare team, you can optimize your nutrition, enhance your well-being, and live a fulfilling life with DMD.

How DMD affects the body and metabolism

DMD primarily affects muscles, causing progressive weakness and wasting. This weakness can affect various parts of the body, including the limbs, heart, and lungs. DMD also impacts metabolism, the process by which your body converts food into energy. Studies have shown that individuals with DMD often have lower energy requirements than those without the condition due to reduced muscle mass and physical activity [2]. It's important to understand that DMD is not just a muscle disease, but also a disease of energy dysregulation [3]. This means that the way your body produces and uses energy is affected. DMD also affects whole-body energy expenditure, which can accelerate disease progression [2]. However, it's crucial to maintain a balanced diet to support overall health and manage specific challenges related to DMD [4].

Studies have identified specific metabolic changes in DMD, including alterations in:

- **Linoleic acid metabolism:** Linoleic acid is an essential fatty acid that plays a role in various bodily functions.
- **D-glutamine and D-glutamate metabolism:** These amino acids are involved in energy production and neurotransmission.
- **Glycerophospholipid metabolism:** Glycerophospholipids are important components of cell membranes.
- **Alanine, aspartate, and glutamate metabolism:** These amino acids are involved in various metabolic processes [5].

General dietary guidelines for DMD

It is important to establish healthy eating habits early on to support your long-term health [6]. Here are some general dietary guidelines for people with DMD:

- **Calorie intake:** Individuals with DMD generally require fewer calories due to decreased physical activity. However, it's essential to monitor calorie intake to prevent both undernutrition and obesity. Undernutrition can worsen muscle wasting, while obesity can put extra strain on already weakened muscles and joints. Your calorie needs will be unique to you and depend on factors like your age, activity level, and whether you are taking steroids. It's best to consult a dietitian for personalized advice.
- **Macronutrient distribution:** Focus on a balanced intake of carbohydrates, proteins, and fats.
 - **Protein:** Protein is crucial for muscle maintenance and repair. Aim for a moderate protein intake, as excessive protein can strain the kidneys. Good sources include lean meats, fish, eggs, dairy products, legumes, and nuts [7].
 - **Carbohydrates:** Choose complex carbohydrates like whole grains, fruits, and vegetables over refined carbohydrates like white bread and sugary snacks [7].
 - **Fats:** Include healthy fats like those found in olive oil, avocados, nuts, and fatty fish [7].

- **Micronutrient Intake:** Ensure sufficient intake of essential vitamins and minerals.
 - **Vitamin D and calcium:** These are vital for bone health, especially for individuals taking corticosteroids, which can weaken bones.
 - **Iron:** Adequate iron intake prevents anemia, which can worsen fatigue.
 - **Antioxidants:** Vitamins A, C, and E protect against oxidative stress, which may be higher in people with DMD.
- **Texture modification:** As DMD progresses, you may experience difficulty swallowing. Modifying the texture of your food can make it easier and safer to eat. This might involve choosing softer foods, pureeing meals, or thickening liquids. We'll discuss this in more detail later in the guide.

Specific nutritional needs for DMD

In addition to the general guidelines, here are some specific nutritional considerations for DMD:

- **Protein:** Given that DMD is a muscle-wasting disorder, preserving muscle mass is crucial. Aim for at least 1 gram of protein per kilogram of body weight [8]. Your doctor or a registered dietitian can help you determine the appropriate amount of protein for your needs.
- **Calcium and vitamin D:** These nutrients are essential for maintaining strong bones [7]. Since DMD often involves decreased mobility and potential use of corticosteroids, which can weaken bones, ensuring adequate calcium and vitamin D intake is crucial.
- **Hydration:** Staying hydrated is vital for overall health and can help manage constipation, a common issue in DMD. Aim for a fluid intake of about half your body weight in ounces per day (e.g., if you weigh 150 pounds, aim for 75 ounces of fluid [7]).
- **Fiber:** A high-fiber diet supports digestive health and can help prevent constipation. Include plenty of fruits, vegetables, and whole grains in your diet.
- **Metabolic acidosis:** It's important to be aware that chronic constipation can disrupt the body's acid-base balance, leading to a potentially life-threatening condition called metabolic acidosis [9]. Managing constipation effectively is crucial to prevent this complication.
- **Creatine monohydrate:** Some studies suggest that creatine monohydrate, a dietary supplement, may help increase muscle strength in children with DMD [1]. However, it's essential to consult with your doctor before taking any supplements, as they can sometimes interact with medications or have other unintended effects.

- **Gastroparesis:** Gastroparesis, or delayed gastric emptying, is a condition where the stomach takes longer to empty its contents. This can cause symptoms like abdominal pain, nausea, and feeling full quickly after eating [9]. Dietary changes, such as eating smaller, more frequent meals, can help manage gastroparesis.

Practical advice and meal planning tips

Now that we've covered the specific nutritional needs for DMD, let's move on to some practical advice and meal planning tips:

- Start the day with a protein-rich breakfast. This can help you feel full and energized throughout the morning [7].
- Increase your water intake. Carry a water bottle with you and sip on it throughout the day [7].
- Avoid foods high in sodium. This can help manage blood pressure and reduce swelling [7].
- Grill, bake, or broil proteins instead of frying them [7].
- Include a salad at lunch and dinner. This is a great way to increase your intake of fiber and antioxidants [7].
- Eat less starchy foods and replace them with less starchy vegetables. For example, instead of a large portion of mashed potatoes, have a smaller portion alongside a larger serving of broccoli or green beans.
- Avoid sweets and sugary foods. Instead, focus on whole, unprocessed foods like fruits, vegetables, and lean proteins.
- Choose foods with a low glycemic index. These foods are digested more slowly and help avoid spikes in blood sugar [7].
- Limit or avoid FODMAPs. These are types of carbohydrates that can be difficult to digest, especially for people with DMD [7].
- Eat smaller, more frequent meals. This can help with digestion and prevent feeling overly full [8].

- If you have difficulty swallowing, consider modifying food textures. Pureed foods, soups, and smoothies can be easier to swallow.

Sample meal plan

Here's a sample meal plan to give you an idea of how to incorporate these guidelines into your diet:

Breakfast:

- Scrambled eggs with whole-grain toast and a side of berries
- Oatmeal with fruit and nuts
- Yogurt with granola and fruit

Lunch:

- Grilled chicken salad with mixed greens, vegetables, and a light vinaigrette
- Tuna salad sandwich on whole-wheat bread with a side of fruit

Dinner:

- Baked salmon with roasted vegetables and quinoa
- Chicken stir-fry with brown rice and plenty of vegetables
- Lean ground beef with whole-wheat pasta and a side salad

Snacks:

- Fruit (apple slices, banana, berries)
- Yogurt
- String cheese
- Unsalted nuts

- Hard-boiled eggs

Tips for Easier Eating and Drinking

Here are some practical tips to make eating and drinking easier if you have DMD:

- Mince hard-to-chew food in a blender. This can make it easier to swallow tougher meats, fruits, and vegetables [10]
- Use straws to make drinking less difficult [10]. Make sure smoothies and other thick drinks are thin enough so that straws don't get clogged.
- Use adapted cutlery. If weakness in your fingers and hands makes gripping cutlery difficult, adapted cutlery can make eating easier [10].
- Choose healthy, soft food snacks. Smooth hummus and yogurt are convenient, healthy snack ideas that don't require chewing [10].

The importance of working with a healthcare professional

It's crucial to work with a healthcare professional, such as a registered dietitian or a doctor specializing in neuromuscular disorders, to develop a personalized nutrition plan. They can assess your individual needs, consider any medications you're taking, and provide tailored recommendations to help you manage your DMD symptoms effectively [11].

Conclusion

Nutrition plays a vital role in managing DMD symptoms and improving your quality of life. By following these guidelines and working with a healthcare professional, you can make informed choices about your diet and support your overall health. Remember that everyone's needs are different, so it's essential to have a personalized plan that addresses your specific challenges and goals. As DMD progresses, your nutritional needs may change, so it's important to stay in contact with your healthcare team and adjust your diet accordingly. A balanced diet, proper hydration, and a proactive approach to managing potential complications can help you maintain your strength, energy levels, and overall well-being.

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