

A man with grey hair and glasses, wearing a white lab coat and yellow gloves, is focused on using a pipette in a laboratory setting. The background is blurred, showing other lab equipment and people.

Medication, Diet, Exercise and Staying Positive

TMA Annual Patient Conference

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Swallowing Difficulties

- The idiopathic inflammatory myopathies are a group of diseases in which inflammation occurs in muscles and often in organs and tissues other than muscle. Included in this group are various conditions whose names contain the term “myositis,” which simply means “muscle inflammation.”
- The throat and upper esophagus consist of muscle identical to the muscles that control voluntary movement. As a result of weakness in these muscles, some patients will develop difficulty swallowing or may aspirate food into the lungs, which can lead to pneumonia.
- Aspiration prevention: Patients who have trouble swallowing must take care to avoid inhaling (aspirating) food and drinks. This may be done by elevating the head of the bed, or by adding thickening agents to drinks.

[Dalakas MC. Inflammatory muscle diseases. N Engl J Med 2015; 372:1734.](#)

Swallowing Difficulties (cont.)

Swallowing difficulties may be caused by dry mouth and/or muscle weakness. They can lead to complications, such as aspiration pneumonia (food getting stuck in the lungs), weight loss, inadequate nutrition and dehydration.

Your medical team *may* recommend:

- Soft foods that are easier to swallow
- Moist foods
- Drinking fluids, which can help in swallowing between bites
- Choosing soups and smoothies (a good way to get fruits and vegetables into your diet) that are pureed to an easy-to-eat or drink consistency
- Keeping a log to determine which foods work best

In general, people with myositis and swallowing difficulties should avoid dry foods, such as crackers, dry cereal and muffins.

https://www.hss.edu/conditions_nutrition-and-myositis.asp



Things to Improve Swallowing

Patients with swallowing difficulties may find that it can be a challenge to follow a balanced diet and get the proper nutrition.

Potential recommendations to make swallowing easier:

- Puree or finely chop well-cooked vegetables, which can then be added to soups.
- Add yogurt to creamed soups or smoothies.
- Add pureed cooked fruit or applesauce to yogurt or hot cereals.
- Season foods with spices that are rich in antioxidants, such as cinnamon, turmeric and ginger.

To manage weight loss, your medical professionals may recommend:

- High-calorie, high-protein nutritional supplements, such as Boost® or Ensure®.
- Adding high-calorie foods to meals, such as olive oil, cheese, pasta and rice.
- Using fortifiers like Carnation® Instant Breakfast in smoothies.

www.hss.edu/conditions_nutrition-and-myositis.asp



Things You Should Eat

Considerations for a Balanced Diet:

GRAINS:

A good, low-fat source of fiber and energy. Whole grains—such as brown and wild rice, whole wheat bread, whole wheat pasta, rye, oats, quinoa, corn and barley—are best, as they also provide a good supply of folate, vitamin B6, vitamin B2, selenium and zinc.

FRUITS AND VEGETABLES:

These contain antioxidants (a group of nutrients that fight free radicals, which can damage cells) and fiber. They are also excellent sources of vitamin C and vitamin A and are naturally low in salt and fat. Fresh or frozen varieties (without sauces) are recommended. If canned fruits and vegetables are consumed, choose low-salt preparations. Intake of dried fruit and fruit juice should be limited because of their high sugar content. Try to have one or more servings of fruit OR vegetable OR both per meal. A single serving is equal to ½ cup of cooked vegetables or fruit, or 1 cup of raw vegetables or fruit.

DAIRY PRODUCTS:

The richest source of calcium, an essential mineral that builds bone and muscle. They are also excellent sources of zinc, B vitamins, vitamin D and selenium. Individuals who are lactose-intolerant (unable to digest lactose in dairy) may choose from lactose-free milk, soy milk, almond milk and other lactose-free products that provide calcium, such as calcium-fortified juices. The goal is to consume three servings of dairy products or dairy substitutes per day.

https://www.hss.edu/conditions_nutrition-and-myositis.asp



Things You Should Eat (cont.)

Considerations for a Balanced Diet:

MEAT, FISH AND POULTRY:

Excellent sources of protein. To meet the recommended guideline of one portion of lean protein at most meals, remove skin from poultry, trim away fat and avoid frying. Instead, broil, roast, poach, or grill these foods. In addition, practice portion control. A serving size should be 4 ounces (about the size of your palm). Meat, fish and poultry are also excellent sources of zinc, B vitamins and iron.

BEANS, NUTS AND SEEDS:

These provide vegetable protein and fiber. They are excellent sources of vitamin E and selenium. Beans are also a healthy meat substitute. Choose unsalted nuts and low-sodium beans including Brazil nuts, wheat germ, flaxseed, soybeans, kidney beans and tofu; walnuts and lentils are also recommended for their high nutritional content.

HEALTHIER FATS:

Foods that provide healthier fats, include monounsaturated oils, nuts, seeds and avocado. Olive oil is a monounsaturated fat rich in the antioxidant polyphenol. Try to limit solid fats, such as butter, stick margarine, shortening and lard as they may contribute to heart disease.

OMEGA-3s:

These are important in the diet, as they may reduce inflammation. Good sources include fatty fish (salmon, sardines, bluefish, mackerel, tuna and halibut), ground flaxseed, walnuts, pecans, canola oil, walnut oil and flaxseed oil. Include these fatty acids in your diet by adding chopped nuts or grilled salmon, tuna or sardines to salads; sprinkle ground flaxseed on cereal or yogurt, and snack on unsalted nuts.

https://www.hss.edu/conditions_nutrition-and-myositis.asp

Exercise and Myositis

What Are the Effects of Myositis?

Differing forms of myositis can have different effects; however the following are common negative physical effects for patients:

- Decrease in muscle mass
- Decrease in muscle strength
- Reduced balance
- Affected gait
- Decreased quality of life

How Does Exercise Prescription Help to Manage Myositis?

Prescribed exercise interventions for patients with myositis can improve the following:

- Muscle mass
- Strength
- Balance
- Gait
- Flexibility
- Quality of life

www.enrichedhealthcare.com.au/library/resources/exercise-myositis.com



Exercise and Myositis (*cont.*)

What Exercises Get the Best Results?

Aerobic exercise:

This assists myositis patients by increasing the function of the cardiovascular system as well as the endurance of the muscles. This can improve the patient's capacity for physical activity, work and activities of daily living and will also improve measures of fatigue. Aerobic exercise may include walking, swimming or riding stationary bikes.

Strength training:

Well-prescribed exercise interventions will increase muscle mass in patients with myositis. Strength training programs will also improve the challenges of balance and gait. Strength training programs can be individually tailored to the patient's needs and can include activities such as lifting free weights.

Balance training:

Balance training can maintain and improve balance for patients with myositis whose balance may be affected by loss of muscle mass or pain.

Remember: Exercise prevents permanent muscle shortening.

www.enrichedhealthcare.com.au/library/resources/exercise-myositis.com



Exercise and Myositis (*cont.*)

There are many forms of exercise a patient can do to remain active:

- Laughter yoga
- Tai chi
- Pool yoga
- Walking
- Pool exercise

Try things that make you feel good and bring you happiness, peace and joy to your well-being while you are doing the activity. It is important that YOU find the activity enjoyable and that the experience is positive.



Medications and Myositis

Corticosteroids:

These dampen inflammation and the immune response by interfering with the processing of antigens and with early triggering of T-cell and B-cell production and later proliferation of B cells and T cells. These cells are produced by the immune system in autoimmune diseases such as PM and DM.

Issues:

- Increased blood sugar
- Weight gain
- Thin skin
- Glaucoma

<http://www.mda.org/disease/dermatomyositis/medical-management>

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Medications and Myositis (*cont.*)

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Azathioprine:

This interferes with proliferation of B cells and T cells. (*IMURAN*®)

Issues:

It can suppress production of several types of blood cells, so cell counts must be monitored; increases risk of cancer.

<http://www.mda.org/disease/dermatomyositis/medical-management>

Medications and Myositis (*cont.*)

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Methotrexate:

This interferes with proliferation of B cells and T cells.

Issues:

It can cause liver damage; used in higher doses to treat cancer.

<http://www.mda.org/disease/dermatomyositis/medical-management>



Medications and Myositis (*cont.*)

Cyclosporine:

This keeps T cells from stimulating production of more T cells and B cells (“upstream” of azathioprine and methotrexate action).

Issues:

High blood pressure, infections, tremors, excessive hair growth

<http://www.mda.org/disease/dermatomyositis/medical-management>



Medications and Myositis (*cont.*)

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Mycophenolate Mofetil (*CellCept®*):

It interferes with proliferation of B cells and T cells.

Issues:

This can cause diarrhea, vomiting, infection (particularly with cytomegalovirus); increases risk of cancer, especially lymphomas; causes depletion of certain blood cells.

<http://www.mda.org/disease/dermatomyositis/medical-management>



Medications and Myositis (cont.)

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Hydroxychloroquine Sulfate (*Plaquenil*):

Mechanism not understood; used in arthritis, lupus, malaria; can be used to reduce steroid dosage in myositis, particularly in children.

Issues:

Can treat muscle symptoms and dermatomyositis rash. Can cause damage to eyes' retinas or corneas; regular eye exams needed.

<http://www.mda.org/disease/dermatomyositis/medical-management>



Medications and Myositis (*cont.*)

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IVIG:

Has complex actions on immune system, such as providing antibodies against patient's own antibodies; interfering with immune system reaction to antibody-marked cells; interfering with blood-transported chemicals released by immune system; interfering with activation and maturation of T cells and B cells.

Issues:

Headache, nausea, excessive hair growth, kidney problems, hypertension

<http://www.mda.org/disease/dermatomyositis/medical-management>

Staying Positive With a Chronic Illness

- People who are ill do best when they focus on what they can control—diet, exercise and decisions about physicians and treatments.
- Attitude is important. Being upbeat all of the time is unrealistic. Have a few people who can listen to you and help you through the tough times.
- Cautious optimism is the best.
- Avoiding the illness can lead to patient to not take care of themselves.




<https://www.psychologytoday.com/blog/21st-century-aging/201212/keeping-positive-outlook-when-dealing-chronic-illnessmclintocktamara>

Benefits of Laughter

1. Lowers blood pressure.
2. Reduces stress hormone levels.
3. Offers a fun abdominal work out.
4. Improves cardiac health.
5. Boosts T cells: When laughing you activate your T cells and it immediately helps you fight illness.
6. Triggers the release of endorphins, which help with chronic pain.
7. Produces a general sense well-being.



A man and a woman are smiling and laughing together. The man is on the left, wearing a dark jacket with a red collar. The woman is on the right, wearing a brown jacket. They are standing in front of a body of water with the Golden Gate Bridge visible in the background. The image has a dark, semi-transparent overlay.

So smile, laugh and live longer

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