

Idiopathic Inflammatory Myopathies (IIM)

Including 2 related types:

- Dermatomyositis
- Polymyositis

Processing a New Diagnosis

A diagnosis of an IIM can be a shock for your child, yourself, parents, siblings, extended family members and friends. Everyone will have different ways of getting through this time but it is important to know that help and support are available for you and your family. Hear advice on processing your diagnosis from a community member with shared experience.

The video is available at <https://youtu.be/A9XM71knDVw>.

Getting help processing a new diagnosis

There are many ways you can seek support as you process a new diagnosis:

- A psychologist is a university-qualified health professional who can help you talk about your thoughts and feelings to understand and cope with the challenges you and your family are facing. Visit our page on **Psychology** for more information.
- A counsellor is a trained professional who can help you talk about and work through problems. Visit our page on **Counselling** for more information.
- A social worker can provide information and support to people experiencing a range of issues including family problems, anxiety, depression, crisis and trauma. Visit our page on **Social Work** for more information.
- Your state or territory neuromuscular organisation can provide support, advice and information about living with IIMs. Visit our page on **state and territory neuromuscular organisations** for more information.
- Your GP can talk to you about a mental health plan and how you can use this to access the help and services you need. Visit our page on **Wellbeing** for more information.
- Other people and families living with IIMs have also experienced the emotional rollercoaster that comes with a diagnosis of an IIM and are able to understand exactly how you're feeling. You are not alone. Connect with other people and families living with IIM in The Loop Community on our **Forum**.

Understanding IIM and How it's Diagnosed

About IIM

Idiopathic Inflammatory Myopathies (IIM) is the name given to a group of conditions caused by inflammation in the muscles or associated tissues. These conditions are non-hereditary, meaning they are not passed down from parents to children. Idiopathic Inflammatory Myopathies (IIM) include dermatomyositis and polymyositis.

What causes Idiopathic Inflammatory Myopathies?

The cause of most cases of IMM is unclear. In IMM the body's immune system (your body's defence system that keeps you from getting sick) turns against its own muscles and causes damage to muscle tissue.

In dermatomyositis, immune system cells attack the small blood vessels that supply blood to the muscles and the skin. In polymyositis, the immune system directly attacks muscle fibres.

What are the main types of IIM?

The two main types of IIM are:

- Dermatomyositis – this condition can occur in childhood or adulthood. In children, onset is usually between the ages of 5 and 14, and girls are affected more often than boys. The most common signs and symptoms of dermatomyositis include skin changes and muscle weakness.
- Polymyositis – this condition usually begins after age 20 and causes muscle weakness that tends to gradually worsen over time.

How is IIM diagnosed?

To diagnose idiopathic inflammatory myopathy, a doctor will consider your symptoms and medical history, and conduct a physical examination to look at the pattern of muscle weakness you are experiencing.

Some tests can be helpful to diagnose IIM or rule out other conditions that have similar symptoms:

- Blood tests: to check the level of creatine kinase (CK), an enzyme that leaks out of muscle fibres when the fibres are being damaged, or specific proteins produced by the immune system
- An electromyogram (EMG): a test in which tiny needles are inserted into the muscles to test their electrical activity of the muscle both at rest and when contracting
- Nerve conduction studies: Studies that measure the strength and speed of a nerve impulse
- Magnetic Resonance Imaging (MRI) scan - used to identify muscles for biopsy and show doctors the pattern of muscle involvement
- A muscle biopsy: involves removing a small piece of muscle for examination under a microscope.

Long-term outlook

Idiopathic Inflammatory Myopathies can cause pain and discomfort for a long period of time. However treatments are available to help manage these conditions and many people will partially or fully recover after a number of years of treatment. Some people can experience some permanent loss of strength and wasting of muscles. In other cases, there can be a full recovery of muscle strength and size. Complications can occur and you may need to be monitored for these (see symptoms). These conditions are generally not life threatening.

For more information about living with IIM, overcoming some of the day-to-day challenges and where to get the right support, visit:

- [Living Life](#)
- [Counselling](#)
- [Social Work](#)
- [Psychology](#)

Understanding and Planning for Changes

Learning about IIM and surrounding yourself with the right healthcare providers, services and support can help you feel more in control of what lies ahead. Although every person's journey with IIM will be unique, the information below will help you understand this journey and how to prepare and plan for changes in the future.

What are the main symptoms of Idiopathic Inflammatory Myopathies?

Symptoms of IIM can include difficulty using stairs, a rash, fatigue and pain in joints and muscles. Weakness in the shoulders, upper arms, hips, thighs and neck muscles can cause symptoms such as difficulty doing your hair, lifting objects or raising your head when lying down.

Symptoms of dermatomyositis include:

- Skin changes - a distinctive reddish or purplish rash commonly develops on your face and eyelids and on knuckles, elbows, knees, chest and back. The rash, which can be itchy and painful, is often the first sign of dermatomyositis.
- Muscle weakness - muscle weakness affecting the muscles closest to the trunk, such as those in your hips, thighs, shoulders, upper arms and neck. The weakness affects both the left and right sides of your body and tends to gradually worsen over time.
- Calcinosis, in which calcium is deposited just under the skin in hard, painful nodules.
- Inflammation of the fat lying just under the skin causes tenderness and feels like little bumps. This is called panniculitis.
- Constriction of the blood vessels around the heart and inflammation of the heart muscle tissue can lead to cardiac complications.
- Inflammation of the lung tissues, causing breathing difficulties.
- Inflammation of the blood vessels of the digestive tract, eyes and kidneys, leading to damage to these organs in some people.

Polymyositis can also affect the heart muscle, causing a condition called inflammatory cardiomyopathy. The muscles involved in breathing may be affected and a few people develop inflammation of the lung tissues. Swallowing problems can also be experienced.

Monitoring

Medical complications involving the heart, lungs, blood vessels and other parts of the body can occur with IIM and adults with IIM should be monitored for:

- Tightening of joints
- Respiratory (breathing) care
- Sleep studies
- Heart issues
- Stomach and bowel problems
- Mental health issues
- Increased cancer risk.

Ongoing monitoring for these possible complications of IIM are necessary and should be discussed with your doctor and specialist.

If you are an adult, your GP or specialist may discuss with you the importance of screening for the possibility of an underlying cancer, as certain types of IIM can be associated with a higher incidence of cancers.

Community Advice

Hear from a community member who has walked the path before you.

The video is available at <https://youtu.be/I7labxjWv9w>.

Life Stuff

To find out more about living life with a neuromuscular condition and to access stories and peer-advice from the community, visit our [Living Life](#) section.

Support for IIM

Treatment and management

The main treatment for IIM are medications that suppress the immune system. Some people may recover completely, while others experience greatly reduced symptoms for long periods of time. It may take a number of years of treatment to achieve

this. Some people, who don't fully recover, may need to take a low dose of medication throughout their lives. It is best to speak with your doctor about side effects of medications and which one is right for you. It may be necessary to trial a number of medications to find one that works for you. Many people eventually recover most or all of their muscle strength and function, although this improvement can be reversed if they stop taking medications.

Physiotherapy and **hydrotherapy** can help with maintaining muscle strength and function. Some people may need to use a walking stick, walker or a wheelchair during acute flare-ups. It is important to consult an occupational therapist to ensure the equipment is suitable for you. Visit our page on **Occupational Therapy** for more information.

Other helpful support services

The video is available at https://youtu.be/BDaCNsd9R_s.

- Your **state or territory neuromuscular organisation** can provide information and advice on what support they can offer such as local support groups, camps, programs, services in the local area, access to cough assist machines, advocacy or assistance in times of crisis. They can also provide an ear to listen if you need someone to talk to or guide you to get the assistance you are needing.
- Seeing a psychologist, counsellor or social worker can be incredibly helpful if you, your child or other members of the family are having a tough time or struggling with negative thoughts and feelings. Learn more about what services are available and how to access them here. Visit our pages on **Counselling**, **Social Work** and **Wellbeing** for more information.
- Other people and families living with IIM have also experienced the emotional rollercoaster that comes with a diagnosis of IIM and are able to understand exactly how you're feeling. You are not alone. Connect with other people and families living with IIM in The Loop Community on our **Forum**.

How to have better conversations when communicating your needs

To learn how to have better conversations when communicating your needs, visit the following pages:

Employers

Educators

Living Life: Education

About IIM

Idiopathic Inflammatory Myopathies fact sheet

From Muscular Dystrophy New South Wales, 2017. This fact sheet includes considerations for future planning.

Support Organisation

Myositis Association Australia

This Australian organisation is dedicated to providing a network of support for myositis patients and their families and assisting myositis patients to manage their condition. Newsletters, meetings and events are held where people can access information and share experiences. The Association also supports research to help find a cure for myositis or improve the quality of life of myositis patients. Promoting awareness for myositis to the health profession and the general public is also a function of the Association.

International Organisations

The Myositis Association (US)

The mission of The Myositis Association is to improve the lives of persons affected by myositis, fund innovative research, and increase myositis awareness and advocacy. Our programs and services provide information, support, advocacy, and research for the myositis community.

Muscular Dystrophy Association (US)

This website has excellent information about neuromuscular conditions, symptoms, causes and care options, as well as a clinical trial finder tool.