Myositis – an inflammatory condition of the muscles

WE ARE VERSUS ARTHRITIS

We're the 10 million people living with arthritis. We're the carers, researchers, health professionals, friends and parents all united in our ambition to ensure that one day, no one will have to live with the pain, fatigue and isolation that arthritis causes.

We understand that every day is different. We know that what works for one person may not help someone else. Our information is a collaboration of experiences, research and facts. We aim to give you everything you need to know about your condition, the treatments available and the many options you can try, so you can make the best and most informed choices for your lifestyle.

We're always happy to hear from you whether it's with feedback on our information, to share your story, or just to find out more about the work of Versus Arthritis. Contact us at **content@versusarthritis.org**

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Contents

Jo's story 4
What is myositis? 6
What are the symptoms of myositis? 8
Other types of myositis 10
How is myositis likely to affect me? 13
What are the possible complications of myositis? 15
How is myositis diagnosed? 16
What treatments are there for myositis? 18
Research and new developments 23
Glossary 24
Useful addresses 25
Where can I find out more? 26
Talk to us 27

Words shown **in bold** are explained in the glossary on p.24.

JO'S STORY

I used to work for a theatre company in London's West End. Before work I'd swim and I often went out in the evenings. We were renovating our first home and I had boundless energy.

One morning I awoke with a swollen knee, soon followed by the other. I went to the GP who did tests. Being diagnosed with **rheumatoid arthritis** and told my right knee needed replacing aged 25 was a shock.

Arthritis spread to every joint. I could hardly walk or get dressed. My arms and legs were getting weak and I had a red rash and swelling everywhere.

One morning my tummy was swollen and stretch marks appeared. My boyfriend (now husband) called the GP for an emergency appointment. I was seen by two GPs and sent to A&E.

By now I looked like the Michelin Tyres character, and was covered head to toe in a red rash. My heart was failing and there was concern for my kidneys.

After a long wait on a trolley, I was admitted to a gynaecology ward – the only bed available! Doctors had no idea why I was so ill, then one evening a consultant said I had dermatomyositis.

I was placed on steroids and immune suppression drugs, and began to improve. I started physiotherapy and hydrotherapy and slowly regained mobility, but would never get back the same function and stamina as before.

Once out of hospital I had help from friends and family. My husband took me to the local pool and eventually I was able to swim in the style of an ironing board!

We got my hands and arms moving again by endless jigsaw puzzles.

Ten years post diagnosis we moved to Norfolk with a view to adopting. I then had my biggest improvement in health. I walked our three dogs daily and took up cycling.

I had 13 years of myositis remission, but then relapsed. My fatigue was so bad, after taking the boys to school in the morning I'd fall asleep at the breakfast table. The next thing I knew, the school secretary was calling to say I was late collecting the boys in the afternoon. It took two years to find the right combination of treatment.

I try to walk regularly, but am slow and breathless. Ralf our cocker spaniel is happy chasing squirrels and returning to check on me.

I was diagnosed before easy access to medical information. My first piece of information was from Laurence Olivier's biography, as he had dermatomyositis. Later I was given a leaflet by Arthritis Research UK. It had details for Myositis UK. This led to contact with Irene, who with her husband, had set up a small charity after their daughter was diagnosed. I felt less alone. I wanted something positive to come from my health situation, so became a trustee for Myositis UK.

I have several milestones coming up, 20 years as a charity trustee, 25 years with dermatomyositis, reaching half century, not out.

What is myositis?

Myositis is the name for a group of rare conditions that can cause muscles to become weak, tired and painful.

The word myositis simply means inflammation in muscles. If something is inflamed, it may be swollen.

Myositis can affect people of any age, including children.

The main muscles to be affected are around the shoulders, hips and thighs.

Having myositis can also lead to other parts of the body being affected, such as the skin, lungs or heart.

Sometimes myositis can affect the muscles that carry out tasks such as breathing and swallowing.

There are several types of myositis. The two most common types are polymyositis and dermatomyositis.

‘Poly’ means many. Polymyositis means that many muscles are affected by inflammation. This type doesn’t often affect other parts of the body much.

Dermatomyositis causes similar symptoms in muscles, but there is also a skin rash. ‘Derma’ means skin.

Polymyositis, dermatomyositis, as well as other types of myositis, are autoimmune conditions.

The immune system is the body’s natural self-defence system. When healthy, it protects us from infection, injury and illness.

However, in people who have autoimmune conditions, the immune system gets confused and mistakenly attacks the body’s own healthy tissues.

One feature of a healthy immune system is inflammation. For example, when we have a cut, the body sends fluid to the affected area so that white blood cells can fight off any infection.

If someone has an autoimmune condition the body can create inflammation when there is no infection to fight. The unnecessary inflammation can then cause problems.

What are the symptoms of myositis?

The symptoms of myositis vary between different people.

They can include:

- weak and tired muscles that can make everyday tasks such as climbing stairs, brushing hair, and getting in and out of cars difficult
- pain in muscles
- muscles feeling tender to touch
- muscles can sometimes swell
- generally feeling unwell
- weight loss
- night sweats.

The most common muscles to be affected are around the shoulders, hips and thighs.

The weakening and tiredness in the muscles can make people with myositis more likely to fall over.

With dermatomyositis you can have the above symptoms as well as:

- a red or pink rash on the upper eyelids, face and neck, and on the backs of the hands and fingers
- swelling of the affected skin
- puffiness and colouring around the eyes.

Some other medical conditions can appear similar to myositis.

These include:

- the side effects of some medications – for example, steroids and drugs to lower your **cholesterol** levels, such as statins
- effects of drinking too much alcohol over a long period
- hormonal conditions – for example, under- or overactive thyroid glands
- low vitamin D levels
- abnormal calcium or magnesium levels
- infections
- other rare muscle conditions – for example, where muscles waste away.

Other types of myositis

Polymyositis and dermatomyositis are the two main types of myositis. Here are some of the others:

Inclusion body myositis (IBM)

Inclusion body myositis (IBM) causes weakness in muscles, usually near the ends of the arms or around the tops of the legs. This can make it difficult to grip objects, or can cause the knee to give way and lead to falls. This condition can also make swallowing difficult.

The effects can happen slowly over 10 to 15 years. It affects more men than women, and generally starts once people are over the age of 50.

The key difference in inclusion body myositis compared to other types of myositis is that as well as inflammation in the muscles, there is also a build-up of protein. These tiny clumps of protein can only be seen with special microscopes. They might not be seen clearly in the early stages of the condition. And so it can be difficult to tell the difference between polymyositis and inclusion body myositis.

Inclusion body myositis doesn't respond to steroids or **disease modifying anti-rheumatic drugs (DMARDS)**, that are used to treat other types of myositis. It's thought that this resistance to treatment is related to the clumps of protein in the muscle cells, which the body cannot break down.

If you're diagnosed with polymyositis and steroids aren't working, you may need further tests to look more closely for inclusion body myositis.

While there are no effective drugs for inclusion body myositis, the following can really help:

- physiotherapy
- regular exercise
- occupational therapy
- speech therapy – if you're having problems with muscles around the throat that makes tasks like swallowing difficult.

Anti-synthetase syndrome

Anti-synthetase syndrome is a condition where several parts of the body are affected by inflammation.

It can affect the muscles, and elsewhere, such as the lungs and skin. This lung condition can potentially be serious, which is why prompt medical treatment is important. Early symptoms can be a dry cough, which can occur before skin and muscle symptoms.

People with anti-synthetase syndrome might also have a condition called Raynaud's phenomenon. In this condition the fingers and toes change colour when cold. They may turn white, then blue and feel very cold to touch. When they warm up again, the fingers and toes may go red and start to throb or swell.

Some people with this condition have in the past incorrectly been told that they have polymyositis or dermatomyositis. It has some similar symptoms, but is now being classed as a separate condition.

Immune-mediated necrotising myopathy

This type of myositis has been discovered more recently. It causes muscle cells to rapidly die in a process called necrosis. Weakness is usually very severe and people with this condition will often struggle to walk and use their arms. In extremely rare cases, this condition can be triggered by statin medication.

Post-infectious reactive myositis

Infectious or post-infectious reactive myositis can occur during and after some viral infections. Even after the virus has gone, the immune system may cause inflammation in some parts of the body for a few months.

Symptoms are similar to those of polymyositis, such as muscle pain and weakness. Usually, the condition is mild and can settle without treatment.

In rare cases, some people who have HIV infection can develop long-term viral muscle infections.

Drug-induced myopathies

Drug-induced myopathies can sometimes appear like myositis. The most common drugs to cause this are statins used to lower people's cholesterol levels. Usually, stopping this drug treatment leads to improvement in symptoms. Occasionally, the symptoms can last after the drug treatment has been stopped and people can develop myositis.

How is myositis likely to affect me?

In most cases the pain and feelings of being unwell are eased with drugs. Even in severe cases most people with myositis eventually respond to treatment.

You may need to try more than one treatment before you find the right one for you.

Muscle strength can take longer to get back to normal. Once myositis is controlled with treatment, exercises can also help to improve muscle strength.

Although people can make a good recovery, some never regain their original muscle strength or function.

Moderate exercise can help you recover muscle strength. Moderate exercise is when you're breathing faster but you aren't straining yourself.

What are the possible complications of myositis?

Sometimes, drug treatments don't work fully and the muscles can remain weak. We are still doing research into why this is the case.

Occasionally, myositis can affect breathing and swallowing. This may occur at the start of severe cases when the muscles used for these important tasks become weak.

On rare occasions, this condition may cause weakening of the heart.

If there is inflammation in the lungs this can cause scarring, which can affect how the lungs work.

Lung and heart conditions can cause long-term breathlessness. For this reason, you may be referred to a heart or chest specialist if there's a risk of these problems developing.

Children with dermatomyositis may develop painful deposits of the mineral calcium in damaged muscles. These deposits, combined with loss of mobility, can occasionally result in permanently rigid joints, which are called contractures.

Polymyositis occasionally occurs in patients who have other autoimmune conditions such as **rheumatoid arthritis**, **lupus** or **systemic sclerosis (scleroderma)**.

On rare occasions, myositis can be associated with cancer. Most people with myositis don't develop cancer, but your doctor might arrange tests such as a chest x-ray or an **ultrasound** scan of your abdomen and pelvis to be on the safe side.

How is myositis diagnosed?

There is no single test that can show for certain if someone has myositis.

Your doctor will talk to you about your symptoms and examine you.

Because the symptoms of myositis are similar to many other conditions you'll probably have blood tests and other examinations.

Blood tests

Blood tests can look for:

- signs of damaged muscles
- inflammation levels within the body
- the presence of **autoantibodies**, which are tiny proteins that can attack the body's own healthy tissues and cells.

There is no autoantibody test that can prove for certain you have myositis, but there are tests that can be helpful in making a diagnosis.

One of these is the anti-nuclear antibody test (ANA). This is a test to see if your blood has **antibodies** that attack the central part of a cell called the nucleus.

Healthy people can also test positive so it's only helpful alongside all the other information about your symptoms.

Other autoantibody tests include ENA (extractable nuclear antigens) and the anti-Jo-1 test. These tests are sometimes positive in people with myositis.

There are now lots of different autoantibodies which can be present in people with myositis. Tests for these can sometimes be useful for predicting your responses to treatment.

Even if these tests haven't led to a diagnosis of myositis, they may have helped your doctor rule out other conditions. There are other tests to help confirm a myositis diagnosis.

Electromyography

You may have a test called electromyography (EMG). This involves a tiny needle electrode, being inserted into the muscle to record electrical messages from nerve endings that enable your muscles to move.

An unusual pattern of electrical activity in a number of different muscles can be due to myositis. The test isn't very painful but may be uncomfortable.

Muscle biopsy

A small sample of your muscle may be taken from one of your larger muscles, for example at the side of your thigh or calf, and examined under a microscope to look for signs of inflammation. This is called a biopsy.

You'll be given a local anaesthetic to numb the area while the sample is taken, but there may be some discomfort for a few days afterwards.

Sometimes, you may need to have another muscle biopsy if your condition doesn't improve with standard treatments. This is to check for the proteins found in inclusion body myositis.

Magnetic resonance imaging (MRI)

An MRI scan can help work out where the inflammation is. Sometimes MRI scans can pick up areas of muscle that are being replaced by fat, indicating damage.

An MRI is a scan that uses magnets to look at what is happening inside your body. It can show soft-tissue damage – in the muscles, ligaments or nerves – as well as any problems with the bones.

What treatments are there for myositis?

Treatment for myositis includes a combination of drug treatment and exercise.

Drugs

The first choice of treatment of myositis is steroids, which are usually given in high doses to begin with.

Steroids can be given as tablets or injections. They should reduce the inflammation quickly, settle muscle pain and the feeling of being unwell.

High doses of steroids can have side effects, so your doctor will reduce the dosage as quickly as possible.

Taking steroids over a long time can increase the risk of developing the condition osteoporosis, which causes bones to become thin and fracture more easily. There are drugs you can take alongside steroids to reduce the risk of developing osteoporosis. This includes bisphosphonates, which can slow bone loss.

Sometimes the symptoms of myositis can flare up when the steroid dose is lowered and your doctor may often prescribe other drugs to help reduce the inflammation. These include methotrexate, azathioprine, ciclosporin, tacrolimus and mycophenolate.

Most of these are types of disease-modifying anti-rheumatic drugs (DMARDs), and you will need regular blood tests to check for possible side effects.

See Versus Arthritis drug leaflets Azathioprine; Ciclosporin; Cyclophosphamide; Methotrexate; Mycophenolate.

Even in severe cases, most people with myositis usually respond well to treatment, although many people need life-long drug treatment to keep their condition under control.

When taking steroid tablets you must carry a steroid card, which records your dose and how long you've been taking it. If you become ill, or are involved in an accident in which you're injured or become unconscious, the steroids must be continued, and the dose might need to be increased. Regular steroid treatment may prevent your body producing natural steroids in response to stress. Your doctor, rheumatology nurse specialist or pharmacist can give you a steroid card.

Occasionally these drugs aren't able to control myositis. In these more severe cases, the following drugs might be available:

- the DMARD cyclophosphamide
- the biological therapy rituximab
- immunoglobulin.

Biological therapies work by blocking specific targets within the immune system that cause inflammation.

Immunoglobulins are antibodies collected from blood donations given by healthy people, which can help stop your immune system from attacking your own tissues. This treatment is usually given as a drip into a vein in your arm, known as an intravenous drip. This will be carried out in hospital and it can be repeated if needed. Sometimes you might feel a little unwell, during the treatment itself.

Even in severe cases, myositis usually responds to treatment, although many people need life-long drug treatment to keep their condition under control.

Exercise and physiotherapy

It's probably best to rest when your myositis is very active, but once it has calmed down doing regular exercise can greatly improve your symptoms and overall health.

Aerobic exercise, which makes you breathe more heavily and your heart beat faster, is especially important to help restore muscle strength and improve stamina.

At first this should ideally be done under the supervision of a **physiotherapist**, who'll give you a tailored programme. You should avoid very strenuous exercise.

Children with juvenile dermatomyositis will need more vigorous physiotherapy to reduce the risk of joints, especially the knees, becoming permanently bent.

People with myositis can make a good recovery. However, some people with severe symptoms may never fully recover.

Even for people who do make a good recovery it can take several months to see improvement, as treatments take time to help your body repair muscles. Because of this you may experience a lot of tiredness.

Continuing to exercise as regularly as you can will greatly help with many aspects of your condition.

It's probably best to rest when your myositis is very active, but once it has calmed down doing regular exercise is safe and can improve your symptoms and overall health.

Research and new developments

Versus Arthritis has funded multiple research studies to further our understanding of myositis.

We've funded research to look at the link between genes people inherit, the presence of certain antibodies and the severity of their condition. This will allow doctors to predict which patients will experience mild or severe disease and why. This will help identify targets for future drug development.

We've also funded research to develop a standard method of assessing children with suspected juvenile dermatomyositis to improve diagnostic techniques, treatment and outcomes for young people. As these conditions are rare, research centres are joining forces to aid recruitment to clinical trials.

We are currently supporting several studies into juvenile dermatomyositis at our centre for adolescent rheumatology at Great Ormond Street Hospital, in London.

This research includes a study looking at the role of a specific white blood cell, a B cell, in myositis. Blood samples will be taken from young people with juvenile dermatomyositis and a group without the condition. The information gathered will improve our knowledge of the condition and may help to develop new and more effective treatments in the future.

Glossary

Antibodies

Antibodies are blood proteins that are produced by your body in response to germs, viruses or any other substances that the body sees as dangerous. The role of antibodies is to attack these unfamiliar substances and make them harmless.

Autoantibodies

Autoantibodies are tiny, harmful proteins that can be present in an overactive immune system. These autoantibodies attack and damage the body's own healthy cells and tissues.

Cholesterol

Cholesterol is a fatty substance, known as a lipid, made in the liver and also absorbed from some foods. In normal quantities it is essential for a properly working body, but if your cholesterol levels are too high it can be harmful to your health.

Disease-modifying anti-rheumatic drugs (DMARDs)

Disease-modifying anti-rheumatic drugs (DMARDs) are a type of drug used to change the way a condition progresses, not just treat its symptoms. Methotrexate, sulfasalazine, infliximab, etanercept and adalimumab are examples of some of the DMARDs used to treat rheumatoid arthritis and other inflammatory conditions. If you're prescribed DMARDs your condition will need regular monitoring.

Lupus

Lupus (systemic lupus erythematosus or SLE) is a condition where the body's immune system attacks healthy cells instead of infections. Lupus can affect the skin, hair and joints, and can sometimes affect the internal organs, such as the heart or kidneys.

Physiotherapist

A physiotherapist is a trained specialist who can help you to remain active and independent by treating problems that affect your movement. They use a combination of exercises, massages and other techniques to help ease pain and keep your muscles and joints mobile.

Rheumatoid arthritis

Rheumatoid arthritis is an inflammatory arthritis that particularly affects the lining of a joint. It commonly starts in the smaller joints usually on both sides of the body – for example, in both hands or both wrists at the same time.

Systemic sclerosis (scleroderma)

Systemic sclerosis is a condition that causes hard, thickened areas of skin on the body. It might also cause problems in your internal organs and blood vessels.

Ultrasound

An ultrasound scan uses sound waves to build up pictures of the inside of the body.

Useful addresses

The following organisations can also help with information and advice on living with arthritis:

Myositis UK

Myositis UK is a charity providing information and support to individuals and families affected by myositis.

Phone: 023 80449708
Email: msg@myositis.org.uk
www.myositis.org.uk

Where can I find out more?

If you've found this information useful, you might be interested in other titles from our range. You can download all of our booklets from our website www.versusarthritis.org or order them by contacting our Helpline. If you wish to order by post, our address can be found on the back of this booklet.

Bulk orders

For bulk orders, please contact our warehouse, APS, directly to place an order:

Phone: 0800 515 209
Email: info@versusarthritis.org

Tell us what you think

All of our information is created with you in mind. And we want to know if we are getting it right. If you have any thoughts or suggestions on how we could improve our information, we would love to hear from you.

Please send your views to **bookletfeedback@versusarthritis.org** or write to us at: **Versus Arthritis, Copeman House, St Mary's Court, St Mary's Gate, Chesterfield, Derbyshire S41 7TD.**

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Talk to us

Helpline

You don't need to face arthritis alone. Our advisors aim to bring all of the information and advice about arthritis into one place to provide tailored support for you.

Helpline: 0800 5200 520
Email: helpline@versusarthritis.org

Our offices

We have offices in each country of the UK. Please get in touch to find out what services and support we offer in your area:

England
Tel: 0300 790 0400
Email: enquiries@versusarthritis.org

Scotland
Tel: 0141 954 7776
Email: scotland@versusarthritis.org

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Tel: 028 9078 2940
Email: nireland@versusarthritis.org

Wales
Tel: 0800 756 3970
Email: cymru@versuarthritis.org

Myositis

Myositis is the name for a group of rare conditions where muscles become inflamed, making them weak, tired and painful. The severity of myositis varies from person to person. In most cases, the condition can be controlled with treatment.

For information please visit our website:
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