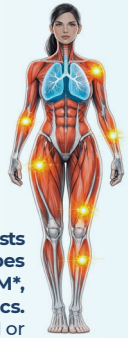
Myositis
Patient Journey

European Reference Network
for rare or low prevalence complex diseases
Network Neuromuscular Diseases (ERN EURO-NMD)

Patient Advisory Board



Physical Health

STEP 1 FIRST SYMPTOMS

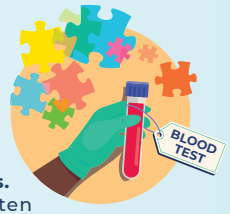
YOU HAVE A RARE DISEASE - BUT YOU ARE NOT ALONE!

Diagnosis Myositis is multi-systemic and consists of various subtypes. These different subtypes of myositis ASyS*, DM*, JDM*, IBM*, IMNM*, OM* and PM* show individual characteristics. Most people with ASyS, DM, JDM, IMNM, OM or PM experience **weakness in the upper arms and/or legs,** usually on both sides of the body. Muscle pain is common, and itching is a frequent symptom in DM. These issues often appear suddenly, causing difficulty climbing stairs, lifting the arms or rising from a chair. **Shortness of breath** may be an early sign in those who develop Interstitial Lung Disease (ILD), which is more common in ASyS and some forms of DM. Many patients also report significant fatigue, joint pain or swelling. **IBM often begins with weakness in the finger flexors and hands,** increased falls due to thigh weakness and swallowing difficulties.

Other early signs may include **muscle wasting, skin redness or the violet-red rash** typical of DM, Raynaud's phenomenon, calcium deposits in the skin or dry eyes and mouth (which can also occur in Sjögren disease). Photos or videos of symptoms can help clinicians with diagnosis. In children with DM (JDM), early symptoms often include muscle weakness, skin rashes, fatigue, irritability and fever.

STEP 2 DIAGNOSIS

DIAGNOSIS IS A PUZZLE



Myositis is a rare, heterogeneous disease that can affect muscles, skin, joints, heart, and lungs. Early symptoms are often vague, so diagnosis may take more or years, especially in inclusion body myositis (IBM).

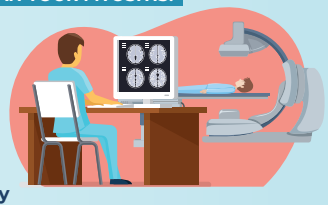
Most patients first see a GP, who may order **blood tests** (ANA, inflammation markers, muscle enzymes or CK) and **assess muscle strength or skin changes.** Depending on the main symptoms, patients are referred to neurology, dermatology, or rheumatology/immunology.

Specialists use targeted tests such as muscle imaging (MRI/ultrasound), EMG, skin or muscle biopsy, lung function tests, ECG/EKG, or swallowing assessments.

A **key diagnostic tool is the myositis blot,** which detects myositis-specific or associated antibodies (MSAs/MAAs). These biomarkers help confirm the subtype, guide prognosis, and indicate risks such as interstitial lung disease or cancer. Because some dermatomyositis subtypes carry higher cancer risk, adults with DM require cancer screening.

STEP 3 FOLLOW UP THE DISEASE

BE STRONGER THAN YOUR MYOSITIS!



Follow-up care is a very important phase of treatment, especially after diagnosis. It should be interdisciplinary and include regular medical checks up that may be comprised of physical examinations, blood tests, and imaging tests. Preferably, it should be done by **the team of specialists in the special medical center.**

People with myositis should have **regular physiotherapy.** Physical exercise has been shown to reduce inflammation and fatigue and increase aerobic capacity and muscle strength, in all types of myositis. It is currently the only treatment recommendation for those with inclusion body myositis."

Effective myositis treatment and patient quality of life depend on strong communication between patients, physicians and general practitioners.

STEP 4 LIVING WITH MYOSITIS

LIVING WITH MYOSITIS IS A CHALLENGE!

Adapting your every day life because of myositis is a challenge: Patients may have many appointments with Healthcare providers. Some activities, e.g. personal care and household chores **take more time and effort.** Sometimes you may need assistance.

Pain and fatigue can occur spontaneously and severely impair the planned daily routine.

Every day is different and you should adapt your everyday life to your illness and think and take care of suitable aids (e.g. rollator, orthesis and carers in advance.

Mental Health

WHAT'S WRONG WITH ME?

Living with myositis isn't just physical— your mental and emotional well-being matters too. Because myositis is complex, getting an accurate diagnosis can take time, and some early symptoms might even be dismissed. **Remember: you know your body best.** Don't hesitate to advocate for yourself or see your doctor as often as needed."

SUDDENLY A LOT/EVERYTHING IS DIFFERENT!

During the time of the examinations, people are afraid that these can cause pain, that a bad result will be found, that no result will be found...

For most people, being diagnosed with myositis is a life changing event!

Many questions arise after the diagnosis is made. For example, to what extent the disease is progressing, how much life will change, what you can still do, whether you can, must and want to take medication? Can you continue to work, can you have children, what happens next?

People might be dealing with feelings of anxiety, low mood or other feelings. **These are a normal response to an abnormal situation.** Talking about these feelings or seeking support helps!

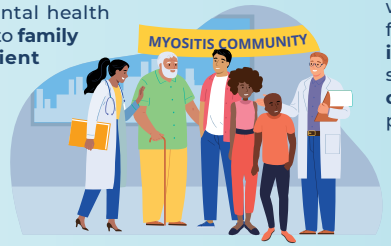
After the diagnosis, people ask themselves whether further tests are necessary and how often they need to see a doctor.

YOU ARE NOT ALONE!

It is not easy to accept the diagnosis and its consequences and to adapt your life accordingly.

It is important that you realise that body and mind should be in harmony with each other. Mental and/or psychological problems can lead to a reduced quality of life, poorer disease outcomes and poorer adherence to treatment.

If you have mental health problems, turn to **family members, patient organisations** and/or **medical professionals** to find the help you need and deserve!



LIVING WITH MYOSITIS IS A CHALLENGE! TAKE UP THIS CHALLENGE!

It takes time and energy to attend appointments with doctors and go to therapy. Organise your resources accordingly. Develop coping strategies to deal with the challenges that you are faced with. **Listen to your body** when it sends you stop signals. **Ask** family members and/or friends **for help if** you need emotional or physical support. **Become part of the myositis community.** Exchange ideas with other patients

More information here:

* Subtypes of Myositis : ASyS = Anti-Synthetase-Syndrom · DM = Dermatomyositis · JDM = Juvenile Dermatomyositis · IBM = Inclusion Body Myositis · IMNM = Immune Mediated Necrotizing Myopathy · OM = Overlap-Myositis · PM = Polymyositis

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