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# Raising myositis awareness

Myositis is a rare disease affecting 1 in 100,000 people in Australia and New Zealand and Myositis Association Australia is calling for greater awareness, in the hope it may lead to earlier diagnosis, better treatments and even a cure.

The four major forms of myositis affecting adults are dermatomyositis, polymyositis, inclusion-body myositis (IBM) and more recently necrotising myositis. Some of the methods used to determine a diagnosis include: MRI of affected muscles, EMG tests, muscle biopsy of the weakest muscle and blood tests.

"With increased awareness, we hope to achieve an earlier and more accurate diagnosis, treatment options and appropriate exercise advice," Anita Chalmers, National Secretary of the Myositis Association said. "As the disease is rare, many doctors are unlikely to have much experience with it. My current GP mentioned he had never seen a case of myositis in his 30 years of practising medicine."

Incorrect diagnosis can also compound the problem, hindering more precise analysis. Symptoms differ between individuals, making the disease hard to diagnose. "There are many concerning stories coming to me about late diagnosis and the 'brushing off' of symptoms," Ms Chalmers said. "Some of our members were told it was 'old age', others said their GP did not understand what they were suffering and gave them anti-depressants and told them to get on with their lives.



*Juvenile myositis can affect children as young as three but the true number of sufferers is unknown. Lachy and Jo (left), along with Frida from Sweden who recently visited Australia, consider themselves "survivors" of juvenile myositis, all being diagnosed in early childhood.*

"In my own case I was told to buy a walking stick because I kept falling down. After changing to a new GP it took two and half years of investigating to try and find out what was wrong. I think I saw about 10 specialists in the Sydney hospital system - all agreed there was something wrong, but for a long time it remained a mystery.

"It was only after my wrist became swollen that my GP sent me for blood tests for rheumatoid arthritis and as the tests showed some anomalies she sent me back for more. Two weeks later, I was diagnosed with polymyositis/dermatomyositis, which was confirmed by a rheumatologist, and treatment was immediately started. This was in 1999. I am now 71 years old, still get around with a walking frame and use a mobility scooter for longer distances.

I am on a maintenance dose of 5mg of prednisolone."

The degree of degeneration for IBM patients can be very significant and requires progressively increasing assisted care, such as lift-up furniture, hoists, elevating wheel chairs, car modifications, treatment for swallowing issues, and elevating toilet seats. The photo on the next page is an example of how hands are affected in the case of IBM. This degeneration can also apply to both polymyositis and dermatomyositis patients.

In many cases, myositis has been associated with other autoimmune disorders of connective tissue such as scleroderma, systemic lupus erythematosus, rheumatoid arthritis, Raynaud's syndrome, and Sjogren's syndrome.

## Typical early signs

- Muscle weakness in thighs and shoulders
- Unexplained general tiredness and fatigue
- Difficulty standing up from a seat or floor
- In cases of IBM, weak grasping of objects and difficulty swallowing
- In cases of dermatomyositis, a reddish-purple skin rash
- Difficulty climbing stairs
- Falling unexpectedly
- In cases of necrotising myositis, there may also be severe pain, swelling, rash/infection, fever, blood pressure changes.



Anita Chalmers



An example of how hands are affected in the case of IBM.

For further information, visit our website [myositis.org.au](http://myositis.org.au) where a 'Physicians Guide to Inflammatory Myopathies' can be found under 'What is myositis' in the menu. Or contact the Myositis Association Australia National Secretary, Anita Chalmers, on 0421 314 138

Ms Chalmers urges all GP's who have patients exhibiting the above symptoms to refer them to either a rheumatologist or neurologist for further study. If you do not know of a specialist who is familiar with myositis, please contact us for assistance.



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call 1300 853 338**

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**8.00am-10.00pm**

**(for the cost of a local call)**

