Dr Jessica McGrath - Paediatric Rheumatologist

Parent and carer information

JUVENILE DERMATOMYOSITIS

STARTING YOUR JOURNEY

Hearing that your child has been diagnosed with *Juvenile Dermatomyositis (JDM)* is understandably a challenging and emotional experience. It can be overwhelming and difficult to process all of the information at once. Please know that you and your child are not alone on this journey.

WHAT IS JDM?

JDM is a rare condition with international studies quoting an annual incidence of 2 to 4 cases in every 1 million children. JDM is an autoimmune condition and is more common in girls than in boys. It often starts between the ages of 4 to 10 years, but children of any age can develop JDM. It is called 'Juvenile' because it is diagnosed before 16 years of age.

The exact cause of JDM is unknown, but researchers believe that it involves a combination of genetic, environmental, and immune system factors.

To understand JDM, we need to first understand the usual role of our body's immune system is to function as a protective "defence force," fighting harmful germs to protect our cells. However, in children with JDM, their immune "defence force" becomes confused. Instead of protecting their cells, the dysregulated defence force launches attack on the small blood vessels that supply skin and muscle; this leads to skin (dermato) and muscle (myos) inflammation (itis).

Autoimmune conditions such as JDM can be unpredictable in nature. Children with this condition require consistent management by specialist doctors, like Dr Jess, to ensure they can get back to running, playing and experiencing the best possible health outcomes longer term.

SYMPTOMS

Children with JDM often experience muscle weakness, pain, rashes and fatigue. Muscles most commonly affected include those close to the trunk of the body (upper arms, thighs), and the trunk itself.

Red rashes can develop over the eyelids and cheeks, as well as other areas of the body (including knuckles, knees and elbows), where the skin may become thickened forming Gottron's papules. Skin ulcers and calcinosis (firm lumps of calcium under the skin) may also occur. Joints may become inflamed as part of JDM. In some rare cases, small blood vessels in other organs (lungs, gut), can also be involved.

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Timely diagnosis and management are essential ways to minimise the long term impact of your child's symptoms and promote their overall well-being.

TREATMENT OPTIONS

Treatment for JDM is tailored to your child's specific needs and will include a multidisciplinary approach with medications and a combination of physical therapy, occupational therapy, and psychological support. The goal is to control symptoms and prevent long term damage, to best facilitate an active lifestyle.

Some of the common medications used in the treatment of JDM include:

Disease-Modifying Anti-Rheumatic Drugs (DMARDs): DMARDs like Methotrexate help control the immune system and suppress inflammation.

Corticosteroids: These are fast acting powerful anti-inflammatory drugs that may be used in the initial treatment phase and during flares.

Intravenous Immunoglobulin (IVIg): IVIg is an intravenous infusion which contains healthy antibodies from blood donors. The exact mechanism by which IVIg modulates the immune system is unknown but is thought to be multifactorial. IVIg is an effective treatment for both skin and muscle disease.

Your child's treatment plan is tailored to their unique needs and symptoms. Dr Jess is there to guide you and places a strong emphasis on family-centred care which plays a crucial role in achieving positive health care outcomes.

FLARES

A JDM flare refers to a period when your child's symptoms become more active and noticeable. During a flare, the inflammation in their skin and/or muscles intensify, leading to increased fatigue, weakness, and discomfort. Triggers for flares are not always clear, but may include factors like excessive sun exposure, illness, stress, or changes in treatment.

Vigilant sun protection with SPF 50+ sunscreen, long sleeves and hat are crucial in flare prevention.

If you believe your child is experiencing a flare, please reach out to our team, do not wait until your next review with Dr Jess.

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PROGNOSIS

Presently, there is nothing we can do to cure JDM but **it is treatable**. Most importantly, there is nothing you could have done, as a parent, to prevent your child from getting JDM.

With timely diagnosis and treatment, most children can achieve an active, healthy lifestyle. For many children, this will take some time from the point of diagnosis to rebuild their strength and stamina.

Treatment is usually continued over a number of years. Whilst JDM is considered a chronic autoimmune disease, many cases of JDM enter complete remission by the time children enter adulthood. Unlike adults with dermatomyositis, JDM is not associated with cancer.

Children with JDM who have involvement of vital organs (e.g. lungs, heart, or gut), have a more severe form of the disease, which in some instances can be life-threatening.

Regular follow-ups with Dr Jess are an important part of your child's JDM care. This can help manage fluctuations in disease by ensuring consistent treatment and disease control.

HELPFUL LINKS AND RESOURCE INFORMATION FOR JDM:

Arthritis Australia - What is Juvenile Dermatomyositis (JDM)
Myositis UK
Printo - Juvenile Dermatomyositis (JDM)

LINKS AND RESOURCE INFORMATION FOR SUPPORT GROUPS:

Australian Rheumatology Association

Arthritis AUSTRALIA

MYOSITIS UK

If your child is acutely unwell please go straight to the Emergency Department or call 000

YOU ARE NOT ALONE, WE ARE ON THIS JOURNEY TOGETHER

Dr Jess & QCC Team

Written and edited by Dr J. McGrath and K.Smith 2023

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