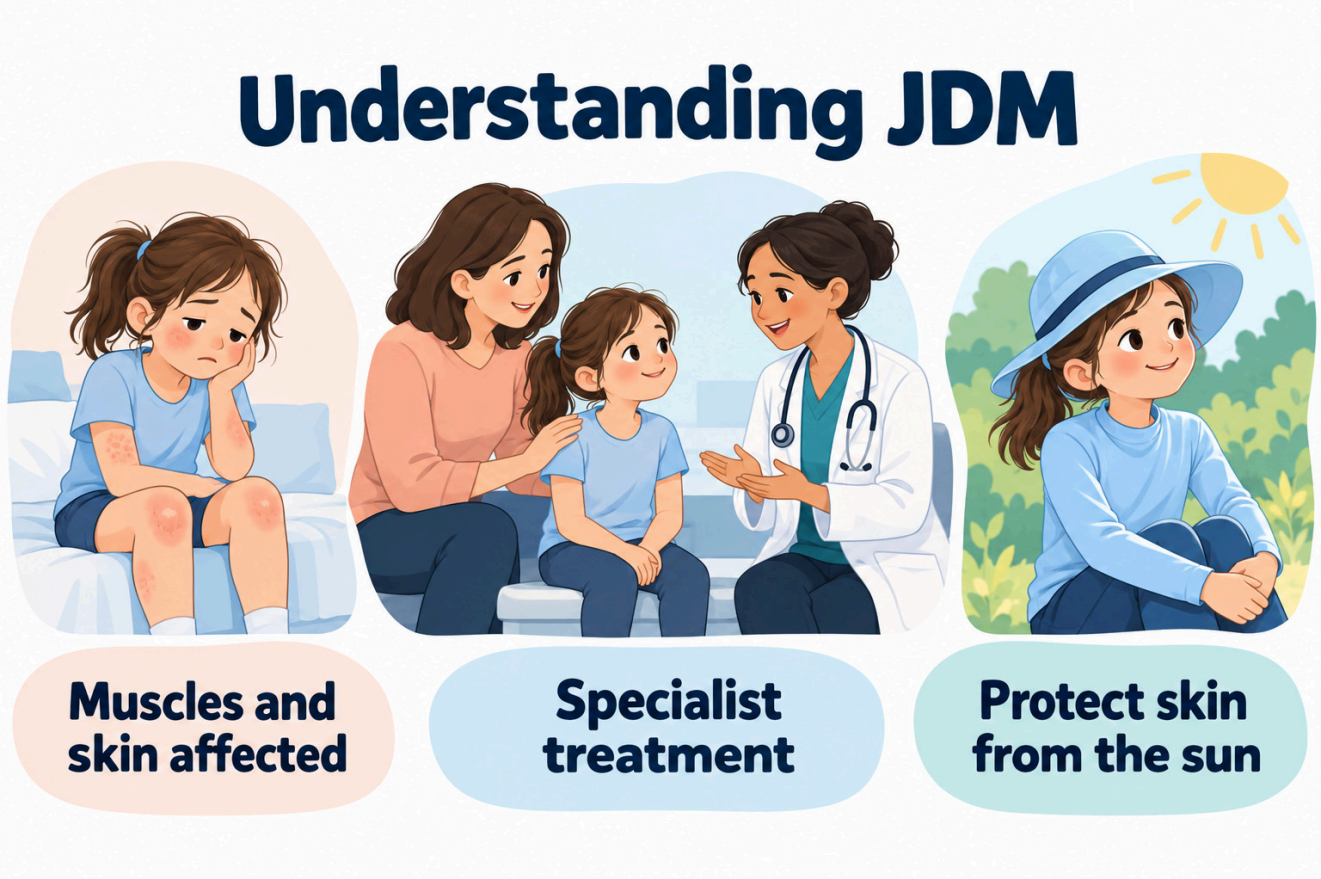
Juvenile Dermatomyositis

Information for children, parents and carers

Juvenile Dermatomyositis

A guide to symptoms, treatment and recovery



Understanding the condition

Juvenile dermatomyositis (JDM) is a rare autoimmune condition causing inflammation in children's muscles and skin. It can cause muscle weakness and distinctive rashes. It is not infectious or caused by injury.

Supporting your child

Early treatment and follow-up with paediatric rheumatology are important. Medicines control inflammation; physiotherapy, sun protection and support at home and school help recovery.

Symptoms and assessment

Understanding the cause and when to seek help

Muscle symptoms

Weakness commonly affects the upper arms, shoulders, thighs and hips. A child may struggle with stairs, getting up from the floor, lifting the arms, running or keeping up with friends. Fatigue is common.

Skin changes

A purple or red eyelid rash, pink or purple bumps on the knuckles, or rash over the neck, shoulders, chest or upper back may occur. Sunlight can worsen skin symptoms.

Other symptoms and causes

Joint pain or swelling, nail-fold redness, tummy pain, weight loss and low energy may occur; swallowing difficulty is less common. The cause is uncertain, involving immune activity, genetics and possible environmental triggers.

How is it diagnosed?

A paediatric rheumatologist assesses strength and symptoms. Blood tests and MRI may check muscle inflammation. A skin or muscle biopsy is sometimes needed. Early diagnosis reduces complications.

Report changes promptly

Contact the healthcare team for worsening weakness, new rash, fever or illness during treatment, medicine side effects, or difficulty breathing or swallowing.

Key message

Early treatment and follow-up with paediatric rheumatology are important. Medicines control inflammation; physiotherapy, sun protection and support at home and school help recovery.

Treatment and daily care

Activity guided by your child's healthcare team

Before starting activity

Activity must be matched to disease control, strength and fatigue. Ask the specialist physiotherapist which movements are appropriate and how to progress them.



Activity guidance

Plan: agree an individual movement and strength programme.
Progress: use the gentle movements taught by the therapist.
Rest: balance activity with recovery and monitor fatigue.
Skin: use sun protection during outdoor activities.

Important precautions

Do not push through worsening weakness or begin strenuous exercise without advice. Tell the team about breathing or swallowing difficulty, fever, new rash or medicine side effects.

Treatment and next steps

Caring for your child and finding support

Medicines and specialist review

Steroids help control inflammation. Methotrexate or other immune treatments may also be prescribed; the team chooses the plan and monitors effects. Keep all follow-up appointments and report illness or side effects.

Physiotherapy and daily support

Therapy supports strength and flexibility. Balance activity with rest and arrange school support for physical difficulties. Recovery may take months and flare-ups may require treatment changes.

Sun protection and nutrition

Use high-factor sunscreen (SPF 30-50), hats and protective clothing, and avoid strong midday sun. A balanced diet with protein, calcium and vitamin D supports health; discuss individual needs with the team.

Questions or concerns?

Contact the team for worsening weakness, rash, fever or illness during treatment, medicine side effects, or breathing or swallowing difficulty. Myositis UK, physiotherapy, OT and school services can offer support.

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