

Juvenile dermatomyositis (JDM)

What is juvenile dermatomyositis?

Juvenile dermatomyositis (JDM) is a rare condition that causes inflammation of the skin and muscle. Inflammation is one of the body's protective responses to infection or injury, but in diseases such as JDM, uncontrolled inflammation can cause damage. Other parts of the body may also be affected such as the lung and intestines.

What causes juvenile dermatomyositis?

The cause of JDM is unknown. It is an autoimmune disease. The immune system usually fights germs or viruses to keep us healthy. Sometimes, the body's immune system mistakes a normal part of the body for something foreign, and starts attacking the body itself (autoimmune). Some doctors think that there may be a combination of genetic factors (something you are born with) and environmental triggers (such as infections). JDM is not contagious or hereditary (passed from parents to children).

What are the symptoms of juvenile dermatomyositis?

The symptoms of JDM may develop over weeks or months, and therefore may be initially difficult to recognise. The severity of JDM can vary from child to child. Most children experience weakness and pain in their muscles. You may notice that your child has difficulty walking up stairs or getting up from the floor. Skin rash is common and occurs over the knuckles, elbows and knees. Rash or redness on the face and around the eyes may also occur. Other common symptoms that your child may experience include: feeling generally unwell, tiredness, irritability, fever, joint pain or swelling, mouth ulcers, swallowing difficulties or voice change. Some children can develop small lumps of calcium under the skin (calcinosis).

How is juvenile dermatomyositis diagnosed?

Diagnosis of JDM is generally based on a combination of the symptoms, physical examination, blood tests, scans (MRI – magnetic resonance imaging) and other tests depending on the body parts involved. There is no specific test to confirm the diagnosis of JDM.

Sometimes a skin and muscle biopsy are required. A biopsy is when a small piece of muscle and skin is taken for examination under a microscope.

How is juvenile dermatomyositis treated?

Your child will be treated with a combination of medicines and physiotherapy. The aim of treatment is to control inflammation and for your child to be free of symptoms. A number of different medications are used.

Steroids can be given by mouth or by infusion (drip) in hospital, depending on the severity of the disease. It is very important never to stop steroids abruptly as your child may become extremely sick.

Other immunosuppressive medicines, such as methotrexate, may be used in combination with the steroids. These types of medications decrease the body's immune response and reduce inflammation. Sometimes a blood product IVIG is given via an infusion.

Physiotherapy is an important part of your child's treatment and will help improve your child's muscle strength and ability to participate in everyday activities. Your child may need therapy with other health professionals such as the clinical nurse specialist or speech pathologists.

How can I help my child?

Follow up: The most important aspect of managing JDM is remembering to give the medicines and to attend clinic for regular checkups. In the beginning your child may need frequent visits to their specialist. As your child's condition improves, the appointments will become less frequent.

Diet: There are no specific recommendations regarding diet for children with JDM. A balanced healthy diet with lots of fruits and vegetables and avoidance of foods high in fat, salt and sugar is the best way to keep well and provide nutrition.

Sun Protection: Sun exposure can trigger a flare of JDM or make the rash worse. Protect exposed areas of your child's skin with a hat, long sleeves and sunscreen.

Vaccinations: It is important to check with your child's doctor or nurse before your child receives vaccinations. If your child is taking immunosuppressive medicines or steroids, live vaccines should be avoided.

Complementary and alternative medicines: At present, there is no evidence to support the use of complementary or alternative medicines in JDM. It is important that your doctor is aware of any other medicines your child is taking.

Living with juvenile dermatomyositis.

JDM can limit your child's usual activities. Your child may have muscle weakness and tiredness for some time. Your child may not feel like going out with friends or going to school. The aim of treatment is help your child feel better so that they can resume their normal activities. Children with JDM may miss a lot of school and this may also affect their schoolwork. It is helpful to let the school know about your child's illness. They may be able to offer support to make things easier.

What is the outlook for my child?

JDM is a chronic (long term) disease and your child may need to be on medicine for a significant period of time, often years.

Treatment usually results in improvement. Your child's progress will be carefully monitored with regular checkups with their rheumatologist, physiotherapist and other health professionals, as well as regular blood tests. Although this is a chronic disease, many children's JDM will resolve by the time they reach adulthood.

Key points:

- Juvenile dermatomyositis is a rare inflammatory disease that mainly affects skin and muscle
- Muscle pain, weakness and rash are common symptoms
- Juvenile dermatomyositis is treated with medications and physiotherapy

Where can I find more information?

Useful websites:

- www.printo.it
- www.rheumatology.org

CONTACT YOUR LOCAL ARTHRITIS OFFICE FOR MORE INFORMATION SHEETS ON ARTHRITIS.

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