

# Oral and Subcutaneous Methotrexate

Information for  
Parents, Carers & Young People



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## Introduction

This leaflet contains information about the use of methotrexate in children/young people for the treatment of juvenile idiopathic arthritis (JIA), juvenile dermatomyositis, systemic lupus erythematosus and other conditions cared for by the Paediatric Rheumatology team.

### It tells you:

- how the medicine works
- how it should be given
- whether there are any side effects

Please also read the general information leaflets available at <http://www.medicinesforchildren.org.uk> or available at the hospital pharmacy. This is in addition to any information provided by the manufacturer in the medicine package.

## Why have I been given this leaflet?

The leaflet will help you to remember what your medical team has told you about this medicine. It will also help you to decide whether you want to go ahead with this treatment.

For most medicines, information is provided by the manufacturer in the medicine package. This medicine does not have a licence for use in juvenile arthritis in children so the leaflet in the medicine package doesn't tell you everything you need to know. We have written this leaflet to give you some extra information.

## What is methotrexate and how does it work?

In JIA and similar conditions the immune system is overactive and attacks normal body tissue, such as the joints. Methotrexate is an immunosuppressant, which means that it dampens down the immune system and slows down/ controls the disease.

Methotrexate is not a pain-killing medicine, so you/your child may need to continue with their pain-killers and non-steroidal anti-inflammatories. Benefit from methotrexate can start as soon as three weeks after starting this medicine, or can take as long as 12 weeks.

## When should methotrexate not be taken?

There are people with certain medical conditions who should not take methotrexate, or who should take it with extra care.

The manufacturers leaflet will explain this in more detail. Please tell your doctor if you/your child has any of the conditions listed.

Please discuss contraception or planning a pregnancy with your doctor or nurse. They can give you information on what risks the medication may cause to you and your baby.

If you think there is a possibility that you are pregnant or your partner may be pregnant please contact your nurse specialist or family doctor immediately.

## How should I give methotrexate?

Methotrexate is given as tablets, liquid or by an injection just under the skin (subcutaneous). The dose may be increased to find the most effective dose for you/your child. Full instructions will be written on the label on the medicine bottle. Please follow these instructions carefully.

Tablets come in two strengths – 2.5mg and 10mg. These look very similar – **always check you have the correct ones.**

Liquids should be 10mg/5ml - **please always check the strength of a new bottle**

Give the dose on the same day ONCE A WEEK. It may help to tick the day you choose on a calendar. Methotrexate is best taken on an empty stomach, but if you/your child complains of tummy ache or indigestion, it can be given with food.

If you forget to give a dose, if it is within 48 hours taken the dose as normal. If it is longer than 48 hours since you missed the dose, miss out the one that you forgot and take the next one on the normal day. If you/your child is sick within 15 minutes of giving a dose, repeat the dose.

You/your child may need to take methotrexate for years. Keep giving the medicine until your/your child's doctor tells you to stop. Do not stop it yourself without talking to the doctor.

## Are there any side effects?

All medicines can cause side effects. The leaflet provided by the manufacturer for methotrexate contains a comprehensive list of the effects reported for this medicine.

Methotrexate may cause nausea or vomiting, indigestion, headaches and diarrhoea. These effects are usually mild and they can settle after a few weeks. Let the Paediatric Rheumatology Team know if your child develops these symptoms which don't go away, as there are measures which can often help.

Mouth ulcers, hair coming out a little more easily with brushing and rarely mood disturbance can sometimes occur. Please discuss any concerns with the Paediatric Rheumatology Team.

You/your child will be required to take folic acid in a tablet or liquid form. Folic acid is a vitamin, which can help to reduce the side effects caused by methotrexate. There are different ways of taking this, but it is never taken on the day of methotrexate. Anti-sickness medications can also be helpful, especially when taken an hour or so before the methotrexate dose.

Methotrexate can very rarely affect the liver, and the blood cell numbers. These concerns can be looked out for with regular blood tests. Blood tests allow any such concerns to be spotted early. The effects always wear off when methotrexate is paused or stopped. Sometimes we need to reduce the dose of methotrexate.

**You/your child must have a blood test every month for three months after the dose is stable. When results are stable the interval can be increased to every three months.**

It is reasonably common for a blood test to show a rise in liver enzymes, which prompts a pausing of the methotrexate and repeating a blood test (to check they have become normal) before re-starting the methotrexate.

Please report easy bruising or easy bleeding. If a worry, this may prompt a repeat blood test.

Methotrexate can suppress the immune system and increase the risk of developing a severe case of chickenpox or measles. If you/your child is on methotrexate and is not known to be immune from chickenpox or measles, but is in close contact with someone that has either of these please contact the paediatric Rheumatology team or your GP.

Please arrange an influenza vaccine every winter, due to the immunosuppressive nature of the medicines. You may also need a pneumococcal vaccine.

As with all immunosuppressant medication we would recommend safe sun exposure, and in particular avoiding sun burn, due to an increased risk of long term skin damage.

Everyone reacts differently to medicines. It is very unlikely that you/your child will have all the listed effects.

## Will methotrexate affect any other medicines?

Methotrexate may affect or be affected by some other medicines. The most common interaction is with trimethoprim (an antibiotic), which can increase methotrexate blood levels and cause problems. There are other drugs that cause a similar effect. You should tell your/your child's doctor or pharmacist about all the other medicines they take. This includes any medicines prescribed by another doctor as well as medicines bought from a pharmacy or supermarket and any herbal remedies.

If you/your child is prescribed a new medicine (including vaccinations), or you want to buy a medicine (for your child) from a pharmacy, it is important that you tell the doctor or pharmacist about all the medicines that they take, including methotrexate. You should also tell you/your child's dentist.

Non-steroidal anti-inflammatory drugs (NSAIDs) can be given with methotrexate under the supervision of the Paediatric Rheumatologist. Do not take/give your child NSAIDs that have not been recommended by the Rheumatologist.

Everyone acts differently to medicines. You/your child may have some side effects or none at all.

## So this medicine may not have a licence. What does this mean?

The leaflet called unlicensed medicines available at <http://www.medicinesforchildren.org.uk/> tells you more about medicine licensing regulations. It also tells you why unlicensed medicines are sometimes used. The injections of methotrexate are licenced medications.

## Why does oral methotrexate not have a licence for use in children?

Sometimes a medicine has been licensed for a certain use in adults and later use shows that it works for a similar illness in children. The manufacturer can choose whether they apply to the Government to have the more recent information added to the licence. This costs a lot of money and sometimes the manufacturer decides it is not worth their while.

Methotrexate is made by the manufacturer for the treatment of arthritis in adults. However it is also widely used in children.

Remember that your doctor will have thought carefully about which medicine is best for your child's condition.

## Where should I store methotrexate at home?

Store methotrexate in a cool, dry place, away from direct sunlight. It is important that all medicines are stored out of reach of children.

## Where do I get a further supply?

Further supplies of oral methotrexate are usually prescribed by your GP. Ask your GP to write a prescription when you have at least a weeks supply left and take the prescription to your local pharmacy in good time.

Sometimes oral methotrexate needs to be prescribed by the hospital team. Subcutaneous methotrexate is prescribed by the hospital team.

## How can I find out more?

This leaflet has been written to provide general information about the use of methotrexate in children. If you have any more specific questions or concerns, please speak to one of the following:

<b>Children's Rheumatology Nursing Team</b>	<b>0113 392 0683</b>
<b>Paediatric Rheumatology Secretary</b>	<b>0113 392 0666</b>





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© The Leeds Teaching Hospitals NHS Trust • 2nd edition (Ver 2)  
Developed by: Paediatric Rheumatology Team  
Produced by: Medical Illustration Services • MID code: 20201111\_001/RC

LN003188  
Publication date  
03/2021  
Review date  
03/2023