

# Use of methotrexate to help with your child's joint, skin or eye condition

## Children's Services

Information for Patients  
Book Number \_\_\_\_\_

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Please bring this booklet to each Clinic appointment

## What is methotrexate?

Methotrexate works by dampening down (suppressing) an overactive immune system.

Low doses of this drug can help with:

- several joint conditions (such as rheumatoid arthritis, psoriatic arthritis and juvenile idiopathic arthritis)
- an inflammatory eye condition called uveitis
- skin conditions such as eczema.

It has been used in children, young people and adults for many years very effectively.

Methotrexate is not a cure. It should help your child's condition by reducing inflammation. It must be taken until your child is completely free of symptoms (in remission). This may take a couple of years.

It can take up to 12 weeks before you see benefits.

We will offer you a clinic session to let you know about the use of methotrexate before it is started. This will give you and your child time to ask questions and talk about any concerns.

There is space on page 13 to write the questions you would like to ask after reading this booklet.

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**Health information and support is available at [www.nhs.uk](http://www.nhs.uk)  
or call 111 for non-emergency medical advice**

Visit [www.leicestershospitals.nhs.uk](http://www.leicestershospitals.nhs.uk) for maps and information about visiting Leicester's Hospitals  
To give feedback about this information sheet, contact [InformationForPatients@uhl-tr.nhs.uk](mailto:InformationForPatients@uhl-tr.nhs.uk)

## How is it given?

Methotrexate is taken by mouth in liquid or tablet form, or as an injection.

When taking it by mouth it should be taken **1 hour after food** with plenty of water or squash.

Your child's consultant will talk to you about the different ways of giving methotrexate. You can agree together the best way for your child to have this medication.

**It is very important that methotrexate is taken once a week on the same day.**

## What are the side effects?

### Feeling or being sick, stomach upset and loss of appetite:

Taking this medicine at bedtime can help with an upset stomach. Your child will not notice it during sleep. It would be best to give it on a Friday night so that school is not affected. Please tell your doctor if the side effects are a problem. We can give an anti-sickness medicine.

### Sore mouth and mouth ulcers:

Your child should brush their teeth well 2 times a day with fluoride toothpaste and a soft toothbrush. This will help with sore mouth and ulcers. Some children find a non alcohol based mouthwash helpful. You should tell your dentist that your child is taking methotrexate.

### Skin rashes, sun sensitivity and slight hair loss:

While taking this medicine, your child's skin may burn more easily in the sun. Make sure your child wears a high factor sunscreen (at least factor 30) and a hat in the sun.

Some people notice more hair loss in their hair brush. This will return to normal when the dose is stopped.

### Lasting cough/ breathing problems:

This is a very rare side effect in children. You should get medical help right away if you think your child has this side effects.

### Effects on the blood:

Very rarely, methotrexate can affect the part of the body that makes red blood cells, white blood cells and platelets. Red blood cells carry oxygen around the body. White blood cells fight infection. Platelets help with clotting. Please tell your child's doctor or nurse if your child seems unusually tired, starts to bruise easily, or gets a temperature above 38°C.

Regular blood tests will show an early warning of these problems, so that the doctor can make changes to treatment.

### Effects on the liver:

It can cause problems with the function of the liver. We do regular blood tests to check the liver.

### Effects on the level of the vitamin folate in the body:

It can lower the levels of an important vitamin in your body called folate. We will give your child **follic acid** to help to reduce side effects of methotrexate. This is usually given once a week, 2 days after their methotrexate dose. This may be increased to help control side affects.

### Why does my child need regular blood tests?

Your child must have regular blood tests whilst taking methotrexate. This is to monitor any side effects. If there are any abnormalities with your child's blood tests, we will let you know. It may mean your child will need more blood tests, reducing the methotrexate dose, or even stopping the dose temporarily.

### Use the table on page 8 to write any changes to your child's methotrexate dose.

Blood tests are done frequently when starting methotrexate. After 3 months if the results have remained stable, blood tests can be spaced out to every 12 weeks.

The day after each of your child's blood tests, you should call your child's specialist nurse to check your child is safe to continue methotrexate.

Page 12 explains which blood tests your child will have and what each one means.

Please talk with the specialist nurse or doctor if you have any questions about your child's blood results.

### You should not give methotrexate:

- if your child's blood results are abnormal
- if your child is unwell and has a temperature over 38°C, or has a rash.

If you do not know whether to give methotrexate or not, always call your child's nurse or consultant for advice.

### Can I give my child other medicines?

Always tell your doctor, dentist and pharmacist if your child is taking methotrexate as it can interact with other medication. For example, a drug commonly used to treat urine infections (**trimethoprim**) can interact with methotrexate. You can give Ibuprofen to your child as they will be having regular blood monitoring to make sure they are safe.

You should not give your child medication containing aspirin. Aspirin is often in many cold remedies. Be careful when buying medication. Speak to your pharmacist if you have any questions about medicines affecting methotrexate.

## What if my child gets chickenpox?

Chicken pox can be more severe and complicated whilst taking methotrexate. If your child does come into contact with chickenpox, please contact your child's nurse or consultant as soon as possible. They may need medication to reduce the risk of getting chickenpox.

You must stop methotrexate if your child has chicken pox. Do this until the spots have scabbed over. Your child will need a specific medication during this illness. You must contact your nurse or consultant for this.

## Can my child get vaccines?

Your child must not to have any 'live' vaccinations whilst taking methotrexate. This includes nasal spray flu vaccine, BCG, MMR, oral typhoid and yellow fever. This is not a full list of live vaccines. You must mention that your child is on methotrexate before getting any vaccine.

You can get the annual flu vaccination. This should be given in injectable form, **but not in nasal form.**

## Can my child get ear/ body piercings?

Piercings often get infected. If your child does have any piercings, you must keep it cleaned as advised. If there are any signs of infection, see your GP right away.

## Information for teenagers/ young adults

Some children continue to take methotrexate into their young adult years. We talk about the following issues when they become teenagers:

### Sexual health and pregnancy

Contraception is very important whilst taking methotrexate. Methotrexate can damage sperm in men and damage egg production in woman. This can cause harm to an unborn baby. When stopping methotrexate, it takes a number of weeks for the drug to leave the body. You must not to get pregnant or plan a family whilst taking methotrexate, or within 6 months after stopping it.

### Alcohol

Alcohol can effect the liver and make the liver more sensitive to methotrexate. As your child becomes more independent and starts going out socially, they must be aware of this and know their safe limit.

## If you will be giving methotrexate by injections

Methotrexate injections are given under the skin where there is a thick layer of fat (subcutaneous injection). We use a needle safe pen device (injection PEN). These injections are often given into the thigh. Having an injection often has less side effects and can be slightly more effective.

We encourage parents and older children to learn how to give these injections. This means they have more flexibility and can continue to have treatment during holidays away.

**Training:** your child's specialist nurse will explain how the injection is given. They will do this using a 'dummy' injection PEN. You, and if appropriate your child, will be given time to practice using the 'dummy' injection device. You can ask questions and talk about any concerns.

We will give full training in how to give this injection. The first injection will often be given in the hospital. You can watch this being given, or give it yourself under supervision having had the training. The next week, your specialist nurse will visit you at home to make sure the injection can be given safely.

**Equipment:** to safely give methotrexate at home we will give you gloves to protect yourself and a 'sharps bin' to safely dispose of the used injection PEN devices. When the sharp's bin is 3/4 full it will need to be returned to the hospital and swapped for a new one.

Never dispose of used injection PEN's or sharps bins in your household waste.

### Injection safety:

**Do not touch the injection PEN if you are pregnant or planning to get pregnant.**

Always check the injection PEN very carefully and only open the box when wearing gloves.

**Do not give the injection if:**

- the injection PEN device is damaged.
- the packaging of the injection PEN is damaged in any way.
- the contents of the injection PEN are cloudy, or not the usual clear yellow liquid.
- any of the details on the label are wrong, like your child's name, drug name and dosage.
- the injection PEN is out of date.

**What to do if methotrexate is spilt:** methotrexate is a cytotoxic drug and precautions should be followed if spilt:

- **On the skin:** wash the area with plenty of soap and water. Do not scrub as this can break the surface of the skin.
- **In the eyes:** wash eyes using plenty of water. Get advice if there is any soreness or changes in vision.
- **On surfaces or floors:** wearing gloves, cover the spillage with absorbent paper to mop up the liquid. Then wash the area with plenty of soapy water. Dispose of gloves, paper and cloths in the sharps bin.

- **On clothing:** blot with absorbent paper. Change clothes and wash them separately to other items.

## Where do I get methotrexate?

Methotrexate is only supplied by the hospital. You will not be able to get this medication from your GP. Make sure you contact your child's nurse when you get down to the last 2 doses of methotrexate. This allows time for a new supply to be arranged.

## Important safety notes

- Always keep all medicines in a safe place and out of reach of children.
- Methotrexate is ok to be stored at room temperature unless the temperature goes above 25 degrees. If the room temperature gets hotter than 25 degrees, it will need to be stored in the fridge.
- Only give methotrexate to your child as you are told by your doctor or pharmacist.
- Be aware that other medication can look like methotrexate, for example folic acid tablets. Check labels carefully before giving your child any medication.
- **Handle methotrexate with care. Wear gloves when touching tablets, liquid and injection PENS.**
- You should not handle methotrexate whilst pregnant.
- If you forget to give your child their dose of methotrexate and it is less than 48 hours (2 days) late, give your child their dose. Return to their usual schedule next week. If it is more than 48 hours late, contact your child's nurse or consultant. **Never double the dose.**
- If your child stops methotrexate treatment or changes their dose, return any remaining medication to your pharmacy. Never throw this away at home.
- Folic acid should ideally be given 2 days after methotrexate or as advised. It should not be given on the same day.
- If your child is having the methotrexate by mouth and they are sick after the dose, do not repeat the dose. Contact your child's nurse or consultant for advice.
- Your specialist nurse or doctor will need to review your child's blood results to make sure methotrexate is prescribed safely. You must take your child for a blood test when advised. If not, this may cause a delay in their next supply of this medication.

<b>Patient name:</b>		
<b>Date of birth:</b>		
<b>Hospital number:</b>		
<b>Clinic name:</b>		
<b>Consultant:</b>		<b>Secretary contact number:</b>
<b>Specialist Nurse:</b> (Monday to Friday, 8am to 5pm)		<b>Contact number:</b>
<b>Pharmacy contact number:</b>		
<b>Blood test appointments -</b> Children's Day Care (say you want to make an appointment for methotrexate blood monitoring)	0116 258 6317  Please let your Child's Specialist Nurse know when this is booked so they know when to check the results.	

## Taking methotrexate

Please remember that methotrexate is **only taken 1 time a week**. Choose a day of the week for your child to have this dose and stick to it. Write it down on the next page to help you remember.

If your child misses their methotrexate on their normal day, don't worry they can take it in the next day or two. For example, if their normal day for taking your dose is Tuesday, they can take it on Wednesday or Thursday. Do not give the dose if it is 3 or more days late. A flare up of the condition during this time is unlikely. In both cases, the next dose should return to the usual day the next week.

Your child should not take any other medication until you have checked with your nurse, pharmacist or doctor that is okay to take with methotrexate. This includes herbal, Chinese and over the counter medication.

Please show this booklet to any doctor's, nurses, dentist or pharmacist that are treating your child so they are aware of your child's treatment.

Your child will also be prescribed folic acid (a vitamin supplement). Your doctor, nurse or pharmacist will advise you when you should take this. Please note that folic acid should not be taken on the same day as methotrexate. Write it down on the next page to help you remember.

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Please keep a record of your child's methotrexate treatment by filling in details of the dose and how it is taken below. For example, number of tablets, number of mls, or size of injection. If the dose changes, for example after a blood test, make sure the new dose is recorded below. Take this new dose, and not the dose shown on the bottle/ label.

[illegible]



## Record of doses Record

Please complete this table each week when methotrexate is due. It is very useful for the Rheumatology team to be able to see this, as it helps them see how your child has responded to this treatment.

Week	Date	Dose	Give Y/N	Reason if not given
1				
2				
BLOOD TEST DUE *				
3				
4				
5				
6				
BLOOD TEST DUE *				
7				
8				
9				
10				
BLOOD TEST DUE*				
11				
12				
13				
14				
BLOOD TEST DUE*				
15				
16				
17				
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23				
24				

Week	Date	Dose	Give Y/N	Reason if not given
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\*This table tells you when blood tests are due when methotrexate is first started. After these dates, if all results have been ok, then blood tests will then be required 3 monthly. This is the standard monitoring and this may change if blood results are abnormal or methotrexate doses are increased.

## Blood test appointments

Date of blood test appointment	Location

**More information on methotrexate can be found at:**

- [www.jia.org.uk](http://www.jia.org.uk)
- [www.ccaa.org.uk](http://www.ccaa.org.uk)
- [www.jarproject.org](http://www.jarproject.org)

## Explanation of the terms used with blood tests

Term and normal value	Explanation
<b>Hb</b> Male: 13.5 – 17.5 g/dl Female: 12 – 16 g/dl	Haemoglobin is the oxygen carrying protein inside red blood cells. Low levels may show that you are anaemic.
<b>WBC</b> 4.0 – 11.0 x 10 <sup>9</sup> /l	White blood cells are important in fighting infections. The count can rise as a result of infection or from taking steroids. A low count may indicate that methotrexate is harming the bone marrow.
<b>Platelets</b> 150 – 400 x 10 <sup>9</sup> /l	Platelets are essential for normal blood clotting. A low count may indicate that methotrexate is harming the bone marrow.
<b>Lymphocytes</b> 1.5 – 4.0 x 10 <sup>9</sup> /l	A type of white blood cell that has an important role in protecting your body from infections.
<b>Neutrophils</b> 2.0 – 7.5 x 10 <sup>9</sup> /l	A type of white blood cell that usually increases quickly to fight infections
<b>ALT / AST</b> Usually less than 50 u/l	ALT / AST are tests to see how your liver is working. Rising blood ALT / AST levels may indicate liver inflammation.
<b>Urea</b> 2.5 – 8.0 mmol/l (varies with age) and <b>Creatinine</b> 60 – 125 µmol/l	These are tests that help to show how your kidneys are working. You will normally have these checked before you start treatment and from time to time (usually every 3 to 6 months) when you are reviewed.
<b>CRP and PV</b>	Indicators of inflammation which may be raised from active disease or infection.

