

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

Children's Services

Information for Patients

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What is methotrexate?

Methotrexate belongs to a group of drugs called cytotoxics. Low doses of this drug can help several joint conditions (such as rheumatoid arthritis, psoriatic arthritis and juvenile idiopathic arthritis), an inflammatory eye condition called uveitis, and skin conditions such as eczema.

Methotrexate works by dampening down (suppressing) an overactive immune system. Methotrexate has been used in children, young people and adults for many years very effectively.

Methotrexate is not a cure, however 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.

Methotrexate may take up to 12 weeks before the benefits are noticed.

You will be offered a clinic session to inform you about the use of methotrexate, before it is started. This will give you and your child time to ask questions and discuss any concerns.

How is it given?

Methotrexate is taken by mouth, in liquid or tablet form. It should be taken 1 hour after food with plenty of water or squash. Methotrexate can also be given as an injection (see page 5). The different ways in giving methotrexate will be discussed with you by your child's consultant, so 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.

**Health information and support is available at www.nhs.uk
or call 111 for non-emergency medical advice**

Visit 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

What are the side effects of methotrexate?

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

It can help to take this medicine at bedtime so the stomach upset is not noticed during sleep; and on a Friday night so that school is not affected. Please tell your doctor if the side effects are a problem, as an anti-sickness drug can be given to help.

Sore mouth and mouth ulcers:

Brushing teeth well twice a day with fluoride toothpaste and a soft toothbrush can help. Some children find an anti-plaque mouthwash also helps. It is important to tell your dentist that your child is taking methotrexate.

Skin rashes, sun sensitivity and slight hair loss:

While your child is taking methotrexate, their skin may burn more easily in the sun. Always 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 whilst taking methotrexate; this will return to normal when the dose is stopped.

On-going cough/ breathing problems:

This is a very rare side effect in children, however medical attention should be sought immediately if you think your child has these side effects.

Effects on the blood:

Very rarely, methotrexate can affect the part of the body that produces red blood cells, white blood cells and platelets (bone marrow). Red blood cells carry oxygen around the body, white blood cells fight infection and 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:

Sometimes methotrexate can cause problems with the function of the liver. This again is checked with regular blood tests.

Effects the level of the vitamin folate in the body:

Methotrexate can decrease the levels of an important vitamin in your body called folate. Your child will be given **folic acid** to help to reduce side effects of methotrexate. This is usually given once a week, 2 days after their methotrexate dose. However this frequency may be increased to help control side affects.

Why does my child need regular blood tests?

It is important that your child has regular blood tests whilst taking methotrexate in order to monitor any side effects. If there are any abnormalities with your child's blood tests, you will be informed immediately. It may mean your child having an additional blood test, reducing the methotrexate dose, or even stopping the dose temporarily.

Use the table on page 7 to record any changes to your child's methotrexate dose.

Blood tests are done every 2 to 4 weeks when starting methotrexate, however after 3 months, if the results have remained stable, blood tests can be spaced out to every 8 to 12 weeks. You will need to record these results in this booklet too.

The day after each of your child's blood tests, you should telephone your child's specialist nurse for the results and **record them in the table for blood test monitoring on page 8. It is important that you record these results and keep it up-to-date.** The pharmacy may also ask for this if you collect a new prescription of methotrexate.

Keeping results of the blood tests will help you to know what is 'normal' for your child, and you will get to know more about this as treatment continues. When checking blood results the doctors and nurses are not only looking at 'what is normal for your child' but also looking for any trends in the blood results that might change gradually over time. These gradual 'trends' can be as important as the 'normal values' set out on page 11.

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

Methotrexate should not be given:

- if your child's blood results are abnormal; a nurse will contact you if this is the case.
- if your child is unwell and has a temperature over 38°C, or has a rash.

If in doubt whether to give methotrexate, always contact your child's nurse or consultant for advice.

Methotrexate and other medicines

Always tell your doctor, dentist and pharmacist if your child is taking methotrexate as it can interact with other medication such as the drug commonly used to treat urine infections (**trimethoprim**).

This is also important when buying over-the-counter medication, as medication containing aspirin should not be taken which is often included in many cold remedies.

Speak to your pharmacist if you have any questions about medicines affecting methotrexate.

Methotrexate and 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, as they may need medication to reduce the risk of getting chickenpox.

If your child develops chickenpox, it is important methotrexate is stopped until the spots have scabbed over. Your child will need a specific medication during this illness, and therefore it is essential you contact your nurse or consultant.

Methotrexate and immunisations

As methotrexate can affect the immune system, it is important not to have any 'live' vaccinations whilst taking methotrexate. This includes nasal spray flu vaccine, BCG, MMR, oral typhoid and yellow fever. Please note this is not a full list of live vaccines and it is important to mention that your child is on methotrexate before any vaccine is given.

The annual flu vaccination is recommended, however this should be given in injectable form, **but not in nasal form.**

Methotrexate and ear/ body piercing

Piercings commonly get infected. If your child does have any piercings, it is very important these are cleaned as advised. If there are any signs of infection, it is important you see your GP immediately.

Information for teenagers/ young adults

Some children take methotrexate in their teenage/ young adult years. It is important that the following issues are discussed with them at an appropriate age:

- **Sexual health and pregnancy**

Contraception is very important whilst taking methotrexate. Methotrexate can damage sperm in men and damage eggs in woman, causing harm to an unborn baby. When stopping methotrexate, it takes several weeks for the drug to leave the body. Therefore it is important not to get pregnant or plan a family whilst taking methotrexate, or within 6 months after stopping it.

- **Methotrexate and 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, it is important that they are aware of this and know their safe limit

If you will be giving methotrexate by injections

Methotrexate injections are given by subcutaneous injection using a needle safe pen device (often called an injection PEN). Subcutaneous injection means an injection just under the skin, where there is a thick layer of fat. These injections are usually given into the thigh.

Giving methotrexate by injection under the skin is an alternative way to having it by mouth. This way often has less side effects and can be slightly more effective.

Parents and older children are encouraged to learn how to give these injections so that they have more flexibility and can continue to have treatment during holidays away.

Training - your child's specialist nurse will fully explain how the injection is given and demonstrate the injection using a 'dummy' injection PEN. You, and if appropriate your child, will be given time to practice using the 'dummy' injection device, and ask questions/ discuss any concerns.

Full training will be provided in how to give this injection, and the first injection will 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 you will be supplied with 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:

If you are pregnant or planning to get pregnant you should not touch the injection PEN.

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

Do not give the injection if:

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

What to do if methotrexate is spilt - methotrexate is a cytotoxic drug and precautions should be followed if spilt. For advice call your GP, the NHS helpline on 111, your specialist nurse, consultant, or children's day care nurses:

- **On the skin** – wash the area with plenty of soap and water; do not scrub as this may break the surface of the skin.

- **In the eyes** – wash eyes using plenty of water. Seek 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 excess 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 affected and wash them separately to other items.

Your supply of methotrexate

Methotrexate is only supplied by the hospital; you will not be able obtain this medication from your GP. Make sure you contact your child's nurse once you get down to the last 2 doses of methotrexate, to allow time for a further supply to be arranged.

Important safety notes

- Always keep all medicines in a safe place and out of reach of children.
- Only administer methotrexate to your child as directed by your doctor or pharmacist.
- Be aware that other medication can look similar to methotrexate, for example folic acid tablets. Check labels carefully before giving your child any medication.
- Handle methotrexate with care. Avoid touching the drug more than needed and wash your hands thoroughly after touching it.
- You should not handle methotrexate whilst pregnant.
- If you forget to give your child their dose of methotrexate, if it is less than 48 hours late, give your child their dose and return to their usual schedule the following 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 pharmacist. Never throw this away at home.
- Folic acid should ideally be given 2 days after methotrexate or as advised, but it should not be given on the same day.
- If your child is sick after their dose of methotrexate, contact your child's nurse or consultant for advice.
- To ensure your child's methotrexate is prescribed safely, your specialist nurse or doctor will need to review their blood results. It is therefore important that you take your child for a blood test when advised, otherwise this may cause in a delay in their next supply of this medication.

Patient name:		
Date of birth:		
Hospital number:		
Clinic name:		
Consultant:		Secretary contact number:
Specialist Nurse: (Monday to Friday, 8am to 4pm)		Contact number:
Pharmacy contact number:		
Blood test appointments - Children's Day Care (say you want to make an appointment for methotrexate blood monitoring)	0116 258 6317	

Taking methotrexate

Please remember that your methotrexate is only ever taken as a once a week dose. Choose a day of the week to take it and stick to it. Write it down on the next page to help you remember.

If you miss your methotrexate on your normal day, don't worry. You can take it the following day or two. For example, if your normal day for taking your dose is Tuesday, you can take it on Wednesday or Thursday. Do not take the dose if you are three or more days late. A flare-up of the disease during this time is unlikely. In both cases, take your next dose on your usual day the following 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 and blood results.

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.

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Blood test monitoring record when taking methotrexate

For an explanation of the terms used with blood results see page 11.

Test date:							
Hb							
WBC							
Platelets							
Neutrophils							
Lymphocytes							
ALT							
Creatinine							
CRP							
PV							

Test date:							
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Explanation of the terms used with blood tests

Term and normal value	Explanation
Hb 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.
WBC 4.0 – 11.0 x 10 ⁹ /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.
Platelets 150 – 400 x 10 ⁹ /l	Platelets are essential for normal blood clotting. A low count may indicate that methotrexate is harming the bone marrow.
Lymphocytes 1.5 – 4.0 x 10 ⁹ /l	A type of white blood cell that has an important role in protecting your body from infections.
Neutrophils 2.0 – 7.5 x 10 ⁹ /l	A type of white blood cell that usually increases quickly to fight infections
ALT / AST 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.
Urea 2.5 – 8.0 mmol/l (varies with age) and Creatinine 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.
CRP and PV	Indicators of inflammation which may be raised from active disease or infection.

Further information

- www.bspar.org.uk
- www.jia.org.uk

If you have any questions, write them down here to remind you what to ask when you speak to your nurse/ doctor/ consultant:

This image shows a blank sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

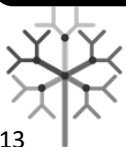
اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔
على هذه المعلومات بلغة أخرى، الرجاء الاتصال على رقم الهاتف الذي يظهر في الأسفل

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ਜੇ ਤਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਭਾਸ਼ਾ ਵਿਚ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਹੇਠਾਂ ਦਿੱਤੇ ਗਏ ਨੰਬਰ 'ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ।

Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu

If you would like this information in another language or format such as EasyRead or Braille, please telephone 0116 250 2959 or email equality@uhl-tr.nhs.uk



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