

Your child's methotrexate

The leaflet aims to answer your questions about your child's methotrexate medication, which they have been prescribed to treat an inflammatory disease. This should be read alongside the manufacturer's leaflet that comes with the medicine.

What is methotrexate?

Methotrexate is a medicine used to treat a range of inflammatory diseases in children. These include juvenile idiopathic arthritis (JIA), psoriasis, dermatomyositis, lupus, scleroderma and uveitis in children. These diseases are all caused by an overactive immune system. Methotrexate has been used in JIA for over 25 years and is the first long term treatment used for active disease that has not responded to simpler therapies.

Methotrexate is known as a "disease modifying anti-rheumatic drug" (DMARD) and it works by dampening down the harmful effects of the immune system. The aim is to produce remission (when the disease has gone away completely) by reducing inflammation. For children with arthritis this reduces pain and stiffness and prevents long term damage to the joints. At the same time it is thought to reduce the body's defence against infection, so it is always used with care.

Methotrexate was originally used in large doses, to treat certain forms of cancer in children. For inflammatory conditions it is given in smaller doses, once a week. These doses help to control inflammation while avoiding many of the side effects seen with larger doses.

How should my child take methotrexate?

Methotrexate can be given as an injection under the skin (sub-cutaneous) or by mouth (as small tablets or a liquid). The best route for your child can be discussed with the Rheumatology Team at the Evelina London (RhEve). Methotrexate is given **once a week** and it is important your child takes it on the same day each week. You should make sure you know what dose your child has been prescribed and a record of this is recorded in your child's RhEve blood monitoring card. Their dose will be calculated on their weight and height.

If your child is taking tablets always check the strength of the tablet you have been given each time you collect a new prescription as there are two strengths, 2.5mg and 10mg tablets that look similar. Usually only 2.5mg tablets are prescribed to avoid any confusion in dose.

Injectable methotrexate is useful, for young children who are unable to swallow tablets or dislike the syrup. If your child's condition does not get better when they are taking methotrexate by mouth, methotrexate by injection can be used since it increases the amount of drug available to your child's body. Parents/carers or older children can easily be taught how to give these injections. Methotrexate may be prescribed by your local GP or local hospital.

How long does methotrexate take to work?

It will not work immediately, usually taking 8 – 12 weeks, before your child will feel any benefit. The dose may need to be increased if there is not a good response, and may depend on your child's rate of growth (remember it is calculated on your child's weight and height). Although any reduction in inflammation may help to reduce pain, it is not a painkiller and other medicines may be needed to relieve pain.

How long will my child stay on methotrexate?

The aim is to produce a remission in your child's disease. Once this has happened we wait approximately one year before reducing or stopping it altogether. Most children are on methotrexate for a minimum of two to three years.

What should my child do if they forget a dose?

If your child misses their methotrexate on their normal day, don't worry. They can be taken on one of the two following days. For example, if your normal day for taking methotrexate is a Friday and they forget, they can take it on Saturday or Sunday. They should not take the dose if they are three or more days late.

In both cases take your next dose on the usual day the following week. If you are unsure of what to do, call the RhEve Helpline for further help (contact details on back page).

What are the possible side effects?

Most children and young people tolerate methotrexate well with few side effects. Possible side effects include:

- nausea with occasional vomiting or stomach upset (approximately 3 in 10 children).
- a sore mouth with ulcers
- effects on their blood count and changes in liver tests
- skin rashes
- thinning of the hair
- mood changes, listlessness and headaches (rare side effects).

Side effects will go once the medication is stopped. At times your doctor/nurse may advise you to stop giving your child methotrexate for two weeks. We will always explain why. Correct monitoring of methotrexate makes sure there is no chance of long term damage to organs.

What should I do if my child has side effects?

The commonest side effects can be managed. For example:

- Consider the time of day methotrexate is taken. If your child has the dose at night then they may sleep through any possible stomach upset.
- Giving your child their medicine on Friday nights means that school and social activities during the week are not missed.
- Consider how methotrexate is given. Many patients prefer the injectable form of methotrexate because it causes less nausea and sickness.
- Your child could try taking folic acid 5mg once a week, two or three days after the methotrexate. This is a vitamin supplement and may help to reduce some side effects. This can be increased up to six times a week (except the day methotrexate is taken) if required.
- Anti-sickness medicines can be prescribed and some children find these helpful.

When should I seek advice about side effects?

It is important to let your doctor know if your child experiences a persistent sore throat, fever, infection or unexplained bruising or any new symptom. Very rarely breathlessness and a cough can occur this too needs reporting immediately.

Does my child need any special checks on methotrexate?

Your child will need regular blood tests at your local hospital or GP during treatment. This will help your doctor see whether methotrexate is causing any side effects. Methotrexate can occasionally affect the blood cell count, causing anaemia or low white blood cells. These blood tests will also check your child's liver function.

You will be asked to hold and record your child's blood results on a RhEve blood monitoring card. Please bring this to every clinic appointment. We would like you to keep this card up to date by asking your GP or local hospital for your child's blood results and recording these on the card. Please contact the RhEve Helpline if your child's results are in the ranges highlighted below, or you have any concerns about your results.

| Abbreviation | Test | Contact RhEve if: | Understanding the results |
|--------------|----------------------|------------------------------------|--|
| Hb | Haemoglobin | Less than 100 g/L | Haemoglobin is present in red blood cells and carries oxygen around the body. Low levels may indicate anaemia, which may be caused by active inflammation, iron deficiency, or as a side effect of medication. |
| Plat | Platelets | Less than 150 x 10 ⁹ /L | Platelets help your blood clot. It is high in active inflammation. Low platelet count may be due to a drug side effect or active lupus. If the platelet count is low you may be at increased risk of bleeding. |
| WBC | White blood cells | Less than 2.5 x 10 ⁹ /L | White blood cells are part of the immune system. They increase during times of infection and inflammation. A low result may be a side effect of medication. |
| Neut | Neutrophils | Less than 1.5 x 10 ⁹ /L | Neutrophils are a type of white blood cell. They increase during times of infection and inflammation. A low result may be a side effect of medication. |
| ALT | Alanine transaminase | More than 120 IU/L | Indicates how your liver is working and if the liver is inflamed. Raised results can be caused by medications, viral infections or inflammation of the liver caused by lupus or another inflammatory disease. |

These tests will be performed monthly for six months, then extend to every two to three months, provided there are no problems. It is important that your child does not miss their blood tests and they must not take methotrexate unless they are having regular blood tests.

Can my child have vaccinations while on methotrexate?

It is safe for your child to have inactivated vaccines such as influenza, meningococcal, pneumococcal, hepatitis, Hib, tetanus, diphtheria, whooping cough and HPV.

Our routine advice is that children should not receive live vaccines such as MMR, BCG, rubella, typhoid, yellow fever, chicken pox and oral polio. If your child needs a live vaccine and there is no alternative available, then this will need to be discussed with the RhEve team. Based on recent studies (and European League Against Rheumatism evidence) we recognise that some live vaccines can be given safely to patients and this will be considered on a case by case basis.

Should my child have a flu jab while taking methotrexate?

We recommend that your child has the annual flu vaccine, which is obtained from your GP. Most children will be offered a nasal spray form of the vaccine. This is not routinely recommended for your child while they are taking methotrexate, as it is a live vaccine. They should instead be given the flu vaccine by injection.

What should I do if my child comes into contact with chickenpox?

If your child has not had chickenpox and comes into contact with or develops chickenpox or shingles, report this to your doctor immediately, because treatment may be required. If you are not sure whether your child has had chickenpox in the past, a blood test can be taken to check your child's immunity (ability to be protected from a particular disease). The result of this blood test should be entered on your child's RhEve blood monitoring card.

The chickenpox vaccines are live vaccines, given before starting methotrexate or on a case by case basis whilst your child continues to take methotrexate. Discuss with the RhEve team if you have any questions.

When should my child not have their methotrexate?

If your child is very unwell with a high temperature, the methotrexate should not be given. If the next day your child has fully recovered, the methotrexate can be given this day instead. Discuss with the RhEve team if your child experiences temperatures as part of their condition, as separate advice will be required. If your child has a general cough or cold the methotrexate can be continued. If unsure of what to do, call the RhEve Helpline for further help – see the contact details on the back page.

Can my child take other medicines while taking methotrexate?

Some medicines interfere with methotrexate, so it is important that you check with your doctor or pharmacist before giving your child new medications. This includes prescribed medications as well as those you can buy without a prescription, and any herbal or alternative medicines.

We routinely prescribe methotrexate and anti-inflammatory painkillers (eg ibuprofen **or** naproxen) for treatment of inflammatory conditions. You should not give your child any anti-inflammatory painkillers without talking to the hospital specialist or GP. These medicines may be found in cold and flu remedies. Paracetamol is fine to have alongside methotrexate.

Your child should avoid certain antibiotics, for example trimethoprim and sulphonamide, while using methotrexate. Always discuss any new medicine with your child's doctor.

Can my child travel with injectable methotrexate?

Most injection pen devices containing injectable methotrexate should be stored at temperatures between 2°C and 25°C, so in the UK room temperature would be fine. However, when travelling to warmer climates, you may need cool boxes and fridges. You may need to keep hospital preparations (pre-filled syringes) in the fridge.

If you are flying, carry methotrexate in your hand luggage for easy access to your child's medication and also because the luggage hold gets too cold. You will need a letter from the nurse specialist or doctor confirming that it is a prescribed medication.

What about my child's future?

If your child remains on methotrexate as a teenager, other issues may become important to you:

- Alcohol intake should be kept to a minimum when taking methotrexate, as it increases the potential for liver damage. Binge drinking is especially damaging. Young people should keep well within national guidelines (two units per day for men and women).
- If your child has taken any controlled substances / illegal drugs, please let the RhEve team know.
- It is important your child does not become pregnant or father a child while taking methotrexate as it is harmful to the unborn baby. Reliable contraception is therefore essential.

Methotrexate will not stop your child having their own children, but will need to be stopped as part of planning a pregnancy. Children who have had methotrexate in very high doses to treat leukaemia, have now grown up and had healthy children.

The future

Methotrexate may eventually be replaced by an even better drug, but for now it represents one of the best advances in treatment for children with rheumatic disease that we have seen in the last 50 years.

It complements the good care provided by a team of doctors, physiotherapists, occupational therapists and nurses who are skilled in the treatment of rheumatic disease, together with the important care provided by your local GP.

Useful sources of information

Children Chronic Arthritis Association

Charity run by parents and professionals to provide a support network for children with arthritis and their families.

t: 01905 745 595

e: info@ccaa.org.uk

w: www.ccaa.org.uk

British Society for Paediatric and Adolescent Rheumatology

Specialist society aiming to advance paediatric rheumatology care in the UK and Ireland. Includes links to lots of helpful websites.

e: enquiries@bspar.org.uk

w: <http://www.bspar.org.uk/info-for-patients>

Contact us

If you have any questions or concerns about methotrexate, please contact the RhEve Helpline on:

t: 07918338768 (mobile number Monday to Friday, 9am to 4pm)
e: RhEve@gstt.nhs.uk

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.guysandstthomas.nhs.uk/leaflets

Evelina London Medicines Helpline

If you have any questions or concerns about your child's medicines, please speak to the staff caring for them or contact our helpline.

t: 020 7188 3003 10am to 5pm, Monday to Friday **e:** letstalkmedicines@gstt.nhs.uk

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk
t: 020 7188 3514 (complaints) **e:** complaints2@gstt.nhs.uk

Language Support Services

If you need an interpreter or information about your care in a different language or format, please get in touch:

t: 020 7188 8815 **e:** languagesupport@gstt.nhs.uk

NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

t: 111

NHS Choices

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

w: www.nhs.uk

Get involved and have your say: become a member of the Trust

Members of Guy's and St Thomas' NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, and to become a member:

t: 0800 731 0319 **e:** members@gstt.nhs.uk **w:** www.guysandstthomas.nhs.uk/membership