

# Methotrexate Information for parents

#### Introduction

Your child has been started on a medicine called methotrexate (meth-oh-trex-ate). This leaflet gives you information about the medicine, the precautions you need to take and the possible side effects.

#### What is methotrexate used for?

Methotrexate is used to help to treat certain rheumatological conditions, such as juvenile idiopathic arthritis (JIA), scleroderma, juvenile dermatomyositis (JDM) and associated conditions including uveitis.

Methotrexate is also referred to as a disease modifying antirheumatic drug (DMARD).

### How does methotrexate work?

Methotrexate is a drug that suppresses inflammation by reducing the activity of the immune system. It is used in low doses for the treatment of rheumatological conditions in children and young people.

## How long will it take for methotrexate to work?

Methotrexate is slow acting; it may begin to have some effect within 3 to 4 weeks but usually takes around 3 months to take full effect. It is important to continue to give your child pain relief as advised by the Rheumatology team. Both naproxen and ibuprofen are safe, paracetamol can be used if needed to top up.

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Methotrexate will need to be taken for a minimum of 18 months to 2 years from the time the inflammation is under control. It is important that you continue to give your child the methotrexate even if you feel it is not working. Please contact your Rheumatology nurse if you have any concerns, the contact details are at the end of this leaflet.

#### How is methotrexate taken?

**Methotrexate is taken once a week** - It is prescribed in tablet or liquid form or given by injection. If your child has been prescribed the injection form this will discussed with you.

Folic acid will also be prescribed, to be taken once a week. This will help prevent any side effects and protect the healthy cells in your child's body.

#### When to take methotrexate

We may suggest giving your child methotrexate at the weekend to avoid any side effects which could affect your child at school. This is only guidance, if a weekend does not suit your family schedule, then you can choose whichever day works best for you. However, once you have chosen a day you must stick to it so that it becomes routine.

As this medication is only given once a week it is easy to forget. If you forget to give your child the methotrexate and it is only 1 day late, then you can go ahead and give the dose then carry on as usual the following week.

If it is more than 1 day late, then we would advise you to miss that dose and give the next on the usual day.

Please remember to give your child the folic acid as well, ideally on the day before the methotrexate is due. This is less important if you forget, as long as you don't give it on the same day as the methotrexate. Giving folic acid on the same day can stop the methotrexate from working properly. Catching up on a missed dose of folic acid is fine at any time.



#### When to miss a dose

There may some weeks when you need to miss giving methotrexate. This may be when the dose has been forgotten, it is more than 1 day late, when your child is unwell or if you have been advised by the Rheumatology team.

- If your child is due the methotrexate but they have a temperature or are acutely unwell, have needed to see the GP and have been prescribed treatment for an infection, the dose can be missed for that week. The methotrexate can be continued as normal when your child has recovered and is well. If the illness is ongoing or you are concerned and need advice, please call or email the Rheumatology nurse.
- If you have been advised to miss a dose, the reasons will be explained to you. The most common reason is an abnormality in your child's blood results which may require the bloods to be rechecked before restarting the methotrexate.
- If your child is due to have surgery, ask your doctor whether you can continue the methotrexate as normal.

## Possible side effects

Most children and young people do not experience problems with methotrexate. However, some parents and young people have noted the following side effects, nausea, vomiting, loss of appetite - usually mild and short-lived. Other side effects include:

- Diarrhoea
- Mouth ulcers
- Skin rash, itching, sun sensitivity
- Slight hair thinning. The hair returns to normal when methotrexate is stopped
- Veruccas, cold sores and ingrowing toenails. These can be more of an issue and you may need medical advice if they persist

If your child is taking methotrexate, it is advised to inform the school in case of any side effects.



Please contact the Rheumatology nurse if you have any concerns about side-effects. Anti-sickness medicines can be prescribed to ease nausea and sometimes the dose of folic acid can be adjusted to reduce symptoms. Changing the timing of the methotrexate to around mealtimes can also ease any nausea.

The earlier we can help with any side effects, the easier they are to manage.

If needed, we can refer your child to our team psychologist. They can talk to you about reducing the impact of side effects and any problems with not wanting to take the medicines. Let us know if you think this would be of benefit.

## **Blood monitoring**

Blood monitoring will need to be done monthly for the first 3 months. If the results are within normal range, then the blood tests can be changed to every 3 months. See separate blood monitoring information leaflet.

## Precautions while taking methotrexate

### **Taking other medications**

Do not give your child any additional medications without consulting your child's GP or Rheumatologist. This is to prevent any potential drug interactions or increased side effects.

## **Drinking alcohol**

Young people should avoid excessive alcohol when taking methotrexate as it can increase the risk of liver problems.

## Effects of methotrexate in pregnancy

Due to the way methotrexate works it can affect the development of the foetus, so pregnancy must be avoided while taking this medication and for 6 months after it has been stopped. Contraception advice should be sought where necessary.



#### Handling, storage and disposal of methotrexate

Care should be taken when handling methotrexate, particularly if you are pregnant. In this case, we recommend that you do not handle the methotrexate if it can be avoided.

You must always wash your hands before and after handling methotrexate.

Methotrexate must be stored at room temperature and kept out of sunlight and out of the reach of children.

Any methotrexate your child no longer requires should be taken to your local pharmacy for disposal. Methotrexate must not be disposed of in house-hold waste.

If your child has been prescribed the injection form of methotrexate you will receive a sharps bin and gloves to safely handle and dispose of the injection devices.

## **Contact with chickenpox**

Methotrexate may reduce your child's ability to fight infections, and therefore if they have never had chickenpox there may be a risk of severe infection from the virus if exposed to it. Before starting methotrexate, a blood test will be carried out to check if there is immunity to chickenpox. Your child may be offered the vaccine if not immune.

## Having immunisations while on methotrexate

Methotrexate may have an effect on the body's immune system, lowering its ability to fight infection. The majority of vaccines in the UK schedule (routine vaccines) are safe to have while being treated with methotrexate.

However, if your child is due their MMR during the expected course of treatment, then please do not allow this vaccine to be given without advice from the Rheumatology team. If you are unsure whether your child can have a vaccination, check with your rheumatology team.



We recommend that your child has the annual flu vaccine:

- If your child is prescribed oral methotrexate either in tablet or liquid form, then the nasal spray flu vaccine may be given at school or if offered, at the GP's surgery.
- If your child has been prescribed injectable methotrexate or they are taking other immunosuppressive medication then the non-live injected flu vaccine must be given by the practice nurses at the GP's surgery.

#### Contact information

Paediatric Rheumatology Nurse: Emma Edmondson

Tel: 07580 931 230

Monday to Wednesday, 9:00am to 5:00pm

Email: emma.edmondson@nhs.net

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## Making a choice

## **Shared Decision Making**

If you are asked to make a choice, you may have lots of questions that you want to ask. You may also want to talk over your options with your family or friends. It can help to write a list of the questions you want answered and take it to your appointment.



## Ask 3 Questions

To begin with, try to make sure you get the answers to three key questions if you are asked to make a choice about your healthcare.

- 1. What are my options?
- 2. What are the pros and cons of each option for me?
- 3. How do I get support to help me make a decision that is right for me?

Ask 3 Questions is based on Shepherd HL, et al. Three questions and Counselling, 2011;84: 379.85.







AQUA https://aqua.nhs.uk/resources/shared-decision-making-case-studies/