

METHOTREXATE

We have written some information to help you understand the treatment planned. This may have already been discussed in a clinic visit or you will be given a specific clinic appointment to talk to one of the specialist nurses. Often there is a lot of information to share and hopefully this information leaflet will be a useful.

What does Methotrexate do?

Some conditions are caused by an over-activity of the immune system. Methotrexate works by helping to calm down the body's immune system. Methotrexate has been used in children, young people and adults for many years and we know that it is very safe and well tolerated.

Methotrexate when given in higher doses is a cytotoxic drug. This means that it can be destructive to cells and therefore can be used to treat some forms of cancer. This is **not** why you or your child is being treated with Methotrexate.

How is Methotrexate given?

Methotrexate is usually given by a small injection under the skin using a 'pinchy' pen device similar to those used for insulin in diabetes.

While it can be given by mouth this is now rarely used as there can be more side effects and it isn't as effective in controlling the medical condition.

How long will it take before Methotrexate starts to work?

It may take between six to eight weeks before there is any improvement in symptoms. In some people it may take up to three months. We often use other medications and treatment to improve symptoms while we wait for Methotrexate to work.

How long is Methotrexate taken for?

The usual practice is to remain on Methotrexate until there has been no sign of active inflammation for 2 years and the rheumatology team will talk to you about this. On average, most young people are on methotrexate for a minimum of 2-3 years.

Which day should Methotrexate be taken?

Methotrexate should be taken on the same day each week where possible. We usually suggest it is taken on a Friday so if there are any side affects you can note if there is a pattern. However it doesn't have to be Friday and can be discussed during your clinic appointment with the specialist nurse.

What will happen if a dose of Methotrexate is missed?

If a dose is missed it can be taken up to 48hrs later. If however more than 48hrs have passed since the dose should have been taken, then miss the Methotrexate that week and start taking it again the following week. Missing one dose doesn't usually cause symptoms of the condition to worsen.

What are the possible side effects?





All medication can have side effects but most patients do not experience them. Most patients tolerate Methotrexate very well. However in some patients Methotrexate can cause a feeling of sickness (nausea), which can progress to vomiting or loss of appetite. The signs are often quite subtle and usually occur over a period of time rather than straight away.

Some patients can be sensitive to Methotrexate and this shows up in their blood tests. We will monitor their blood tests closely for 3 months and if there are no issues we will try to time blood tests every 3 months when a clinic review is due

Lung problems with shortness of breath have been reported in adults, but this is extremely rare in children and young people.

Can other medication be taken safely along with Methotrexate?

Most medication can be safely taken with Methotrexate. However some drugs such as antibiotics (Co-Trimoxazole and Trimethoprim) do interact with it. It is therefore a wise precaution to tell the doctor, dentist, or pharmacist prior to taking other medications, to ensure that they do not interact with Methotrexate. This also includes herbal remedies.

Can someone taking Methotrexate have immunisations?

Vaccines are classed as inactivated or live. The immunisation schedules do change but currently:

- 1. Inactivated vaccines: tetanus, meningitis C and diphtheria etc. are <u>safe to have</u> when taking Methotrexate.
- 2. Most live vaccines (such as, nasal flu, BCG and varicella) should not be given, but MMR booster (usually given at around 3 yr. 4 mths of age) is safe while on methotrexate.
- 3. If someone taking Methotrexate is planning to visit a foreign country where vaccinations are needed, they will need to avoid live vaccines and should discuss this with their GP or practice nurse.
- 4. If someone who is due to start taking Methotrexate has not had chicken pox in the past if possible we will advise they have chicken pox vaccination before starting Methotrexate.

What monitoring is needed when taking Methotrexate?

Methotrexate can affect the blood count and can sometimes cause problems with the liver. It is therefore important that blood tests to check these are carried out regularly and this will be arranged by the rheumatology team. On starting treatment these are done every month for 3 months and then every 3 months if stable and normal. We have a monitoring clerk Alison who makes these arrangements and will call you if the blood tests need repeating. We do not notify everyone on Methotrexate if their bloods are normal.

Sometimes a mild illness e.g. a cold or sore throat this can alter the blood tests. If this happens a nurse or monitoring clerk will ring and offer advice. Often the methotrexate is stopped for 2 weeks and the blood test repeated. This is just a precaution and shouldn't alarm you.





What about the risk of infections whilst taking Methotrexate?

Methotrexate can dampen down the body's ability to fight infections in some people. Therefore people taking it may find they take longer to get over infections like coughs and colds. From experience we also know that many patients on methotrexate do not pick up infections more than anyone else as their immune system works more effectively when on treatment than it did when the condition first appeared.

Checking their temperature is also a useful guide to detect signs of illness. We recommend you have a thermometer in your house. A normal temperature is between **36-37** degrees. If someone gets a more serious infection or if their temperature rises above **38°C** they should seek advice from the specialist nurses or doctor/GP within 24 hours as they may need antibiotics or further treatment.

Chickenpox

If someone on Methotrexate has never had chickenpox they may be at risk of a more severe version of the virus that causes chickenpox and shingles.

Chickenpox tends to be an issue for younger children. From exposure to developing spots is usually between 7 and 21 days. Often the child has cold type symptoms and is generally off colour before the spots appear. Spots usually appear on the body in a small group before becoming more wide spread. Some children only have a few spots while others can have lots of spots.



Before starting Methotrexate a blood test is usually carried out to test if they are immune (resistant) to chickenpox as there may be an option of being vaccinated before starting Methotrexate. This will be discussed with the team.

If your child is not immune, and is unable for some reason to be immunised specific advice will be given on how to look after your child. In the younger age group they will almost inevitably come into contact with a friend or family member with chickenpox. Please don't worry too much about this. If you know they have been exposed we advise you to check your child each morning and bedtime for signs of spots. If you can't contact us you should seek advice from your GP or out of hours service, explaining your child is on methotrexate and you are concerned they may have chickenpox.

If your child develop chickenpox or shingles, contact your paediatric rheumatology team, GP or out of hours service as soon as possible as they will require special treatment.

Will Methotrexate stop the pain?

Methotrexate is not a pain-killing drug, so anti-inflammatory drugs or pain-killers may be needed for a while whilst the Methotrexate starts to work. However, once the Methotrexate is working, and the inflammation has settled down, the pain is usually much better so most people find they can stop their painkillers.





For those patients with arthritis often joints may look swollen and sore but pain isn't always an issue for many patients. The joint is often stiff and doesn't move very well however children and young people are very good at adapting. This is partly why it can take a long time to get the diagnosis.

Can alcohol be drunk by people taking Methotrexate?

There is no known safe drinking limit for children, let alone children taking Methotrexate. Most units would suggest an adult taking Methotrexate should drink less than 5 units of alcohol a week and we recommend an older teenager should not be drinking more than 2-3 units / week. That is an upper limit each week and cannot be "saved up" so as to drink more in future weeks. More advice will be given to young people during their clinic appointment with the specialist nurse as many people don't know what a unit of alcohol actually is.

Can a person taking Methotrexate have any tattoos or piercings?

We would strongly recommend that patients taking Methotrexate do not have any tattoos or any piercings done without discussion with the specialist nurses. Piercings, particularly in areas such as the mouth or belly-button, are prone to get infected and can become badly scarred. However we can discuss the timing of ear piercing with you if the person on Methotrexate is stable and well.

What will happen if someone taking Methotrexate gets pregnant?

Methotrexate does not make either men or women infertile or act as a contraceptive. Methotrexate can cause severe damage to the unborn baby. For this reason when anyone taking Methotrexate and is having a sexual relationship it is vital they use a reliable form of contraception. The specialist nurses will discuss this in more detail often alone with the young person.

If I am pregnant can I still give my child their injection?

Health and safety advice recommends if possible, if you are pregnant, planning a pregnancy or breast feeding it is advisable not to administer Methotrexate to your child. If this is not possible the specialist nurse will discuss the other options available to you.

What should be done if Methotrexate is accidentally spilled?

- Spillage in eyes: Wash the eyes using plenty of water and contact your doctor for advice if you experience any side effects.
- Spillage onto floors and work surfaces: cover the spillage using absorbent paper; wipe
 the area clean with water, then soap and water. All paper/cloths etc. should be put in
 the special bin provided.
- Spillage onto clothes: Blot dry with a paper towel. As a precaution, clothing should be changed and washed separately to other items.

How do we get Methotrexate and how is it stored?





We will give you the first prescription and it will need to be stored at room temperature in a cupboard out of reach of children. We will then arrange for a home care company to contact you and arrange delivery every 3 months. They will also give you a new sharps bin.

Top tips about Methotrexate

- Methotrexate should only ever be taken once a week. Taking it more frequently can be dangerous
- Always take the exact dose prescribed by your doctor
- Always attend for the regular blood tests whilst taking Methotrexate
- Seek advice from a doctor or the rheumatology team if the person taking Methotrexate develops chicken pox.
- If the person taking Methotrexate has a raised temperature (more than 38°C) seek advice from the rheumatology team or GP before taking the methotrexate
- The patient taking Methotrexate must not have most live vaccinations whilst on Methotrexate.
- Do not handle Methotrexate if possible if you think you might be pregnant or are breast feeding
- Do not get pregnant, or get anyone else pregnant, whilst on Methotrexate
- Beware of alcohol intake

Further information

If you require further information or you have any worries regarding possible side-effects please contact your rheumatology nurse or doctor.

This fact sheet only gives general information. You must always discuss your individual treatment with the appropriate member of staff.

September 2020



