

Sulfasalazine

Information for
Parents, Carers & Young People



leeds children's
hospital

caring about children

Introduction

This leaflet contains information about the use of sulfasalazine in the treatment of juvenile idiopathic arthritis (JIA) in children/young people.

It tells you:

- how the medicine works
- how it should be given
- whether there are any side effects.

Please also read the general information leaflets available at <http://www.medicinesforchildren.org.uk> or available at the hospital pharmacy. This is in addition to any information provided by the manufacturer in the medicine package.

Why have I been given this leaflet?

The leaflet will be used alongside discussions with your doctor about this medicine. It should help you to decide whether you want to go ahead with this treatment.

For most medicines, information is provided by the manufacturer in the medicine package. This medicine does not have a licence for use for in juvenile arthritis in children so the leaflet in the medicine package may not tell you everything you need to know about the use of the medicine for this condition. We have written this leaflet to give you some extra information.

What is sulfasalazine and how does it work?

Sulfasalazine reduces the inflammation process in JIA and slows down the development of the disease. It is mainly used for the enthesitis related arthritis subtype of JIA.

Sulfasalazine is not a pain-killing medicine, so you/your child may need to continue with their pain-killers and non-steroidal anti-inflammatory drugs. It works slowly and it often takes between two and four weeks before it starts to work. Usually progress is reviewed after 2 or 3 months to see if it is helped. There is a chance that sulfasalazine will not help disease control.

When should sulfasalazine not be taken?

People with certain medical condition should not take sulfasalazine, or should take it with extra care. The manufacturers leaflet will explain this in more detail. Please tell your doctor if you/your child has an allergy to aspirin or sulphonamide antibiotics

Guidelines state that it's safe for women to continue using sulfasalazine when trying for a baby and during pregnancy. It's often recommended that you continue sulfasalazine throughout pregnancy to prevent flare-ups.

If you're pregnant and taking sulfasalazine, you should also take folic acid tablets. This is because sulfasalazine can reduce levels of folic acid in the body.

Sulfasalazine is considered safe to use while you are breastfeeding, unless the baby is premature or at risk of jaundice. Speak to the rheumatology team about this if you have any concerns.

Sulfasalazine can cause a fall in sperm count, but must not be relied upon for contraception. This effect is reversed if treatment is stopped. Talk to your doctor as soon as possible if you are planning a family, or if you become pregnant while taking sulfasalazine.

How should I give/take sulfasalazine?

Sulfasalazine is given in tablet or liquid form. The tablets and liquid can be taken at any time of the day, preferably with food. The tablets should be swallowed whole with plenty of water. They should not be crushed or chewed. Full instructions will be written on the Pharmacy label on the medicine bottle. Please follow these instructions carefully.

If you forget to give/take a dose, give it as soon as you remember. If it is nearly time for the next dose, miss out the forgotten dose.

If your child is sick within 15 minutes of giving/taking a dose, repeat the dose.

Sulfasalazine may be needed for years. Keep giving the medicine until the doctor tells you to stop. Do not stop it yourself without talking to the doctor, unless you are worried: in which case please get in touch with the Paediatric Rheumatology team.

Are there any possible side effects?

All medicines have possible side effects. The leaflet provided by the manufacturer for sulfasalazine contains a list of the effects reported for this medicine.

Most children tolerate sulfasalazine well. However, the commonest side effects include dizziness, feeling sick, rash, sore mouth, bruising and headaches. Let the Paediatric Rheumatology team know if you are having any concerns.

Sulfasalazine may colour the urine yellow or orange. There is no need to worry about this. It can also stain soft contact lenses, so glasses may be needed instead.

Sulfasalazine can rarely affect the liver, kidneys and blood. These effects can be checked with a blood test. Whilst taking sulfasalazine children/young people must have a blood test every month for three months and then every three months after that.

Everyone reacts differently to medicines. It is very unlikely that you/your child will have all the listed effects.

As with all immunosuppressant medication we would recommend safe sun exposure, and in particular avoiding sun burn, due to an increased risk of long term skin damage.

Will sulfasalazine affect any other medicines?

Sulfasalazine can be taken safely with most other medicines. However, you should tell the doctor or pharmacist about all the other medicines they take. This includes any medicines prescribed by another doctor as well as medicines bought from a pharmacy or supermarket and any herbal remedies.

If you are/your child is prescribed a new medicine whilst taking sulfasalazine, or you want to buy a medicine (for your child) from a pharmacy, it is important that you tell the doctor or

pharmacist about all the medicines that they take, including sulfasalazine. You should also tell your/your child's dentist.

Please arrange an influenza vaccine every winter, due to the immunosuppressive nature of the medicines. You may also need a pneumococcal vaccine.

So this medicine does not have a licence. What does this mean?

The leaflet called unlicensed medicines available at <http://www.medicinesforchildren.org.uk/> tells you more about medicine licensing regulations. It also tells you why unlicensed medicines are sometimes used.

Why does sulfasalazine not have a licence for use in children?

Sometimes a medicine has been licensed for a certain use in adults and later use shows that it works for a similar illness in children. The manufacturer can choose whether they apply to the Government to have the more recent information added to the licence. This costs a lot of money and sometimes the manufacturer decides it is not worth their while.

Sulfasalazine is made by the manufacturer for the treatment of rheumatoid arthritis in adults. However it is also widely used in children.

Remember that your doctor will have thought carefully about which medicine is best for your/your child's condition.

Where should I store Sulfasalazine at home?

Store sulfasalazine in a cool, dry place, away from direct sunlight.

It is important that all medicines are stored out of reach of children.

Where do I get a further supply?

Further supplies are available from your GP. Ask your GP to write a prescription when you have at least a weeks supply left and take the prescription to your local pharmacy in good time.

How can I find out more?

This leaflet has been written to provide general information about sulfasalazine in children. If you have any further questions or concerns, please speak to the Paediatric Rheumatology team.

Useful contact numbers

Children's Rheumatology Nursing Team	0113 392 0683
Paediatric Rheumatology Secretary	0113 392 0666



What did you think of your care? Visit bit.ly/nhsleedsfft
Your views matter

© The Leeds Teaching Hospitals NHS Trust • 1st edition (Ver 2)
Developed by: Paediatric Rheumatology Team
Produced by: Medical Illustration Services • MID code: 20201110_014/RC

LN004708
Publication date
11/2020
Review date
11/2023