

Great Ormond Street Hospital for Children NHS Foundation Trust: Information for Families

Immunosuppressant medicines to treat immune-mediated neurology conditions

This information sheet from Great Ormond Street Hospital (GOSH) explains about the use of immunosuppressant medicines to treat immune-mediated neurology conditions, how they are given and some of the possible side effects. Each person reacts differently to medicines, so your child will not necessarily suffer from the side effects mentioned. If you have any questions or concerns, please speak to your doctor, nurse or pharmacist.

This information sheet should be read in conjunction with any patient information leaflet provided by the manufacturer. However, please note that this information sheet explains about the use of the medicines in children and young people so may differ from the manufacturer's information.

What are immunosuppressant medicines?

Immunosuppressant medicines 'damp down' the immune system, with the aim of controlling inflammation. Your child will not notice any immediate effects of taking immunosuppressant medicines as they take some weeks to start working. Most children take immunosuppressant medicines for two to three years. When your child has been in remission for a year or two, the dose may gradually be reduced and then stopped.

There are two main types of immunosuppressant medicines used to treat immune-mediated neurology conditions:

- Azathioprine
- Mycophenolate mofetil

How are they given?

Both azathioprine and mycophenolate mofetil are taken by mouth.

Azathioprine is available as generic (unbranded) tablets of 25mg and 50mg strength as well as under the brand name Imuran®. Azathioprine is also available as a 'special' in the form of oral liquid suspension. This means that the preparation has to be specially made and so may not be readily available from your local community pharmacy.

Supplies of this medicine may take longer than usual to obtain, usually several days, but in some cases, a couple of weeks.

Mycophenolate mofetil is available as tablets of 500mg strength, 250mg capsules and oral suspension of 200mg/ml. It is also available as a gastro-resistant coated tablet, which takes longer to be broken down in the stomach, in 180mg and 360mg strengths under the brand name Myfortic®.

Who should not take azathioprine or mycophenolate mofetil?

People with the following conditions should discuss taking azathioprine or mycophenolate mofetil with their doctor:

- Hypersensitivity to the medicine or any of its ingredients
- Pregnant, could be pregnant, trying to become pregnant or breastfeeding
- Existing digestive system disorders
- Existing kidney problems

What are the side effects?

Alteration in blood count – Both azathioprine and mycophenolate mofetil can affect your child's blood. This will be monitored by regular blood tests. If you notice any unexplained bruising, bleeding, sore throat, temperature or other signs of infection, please contact your family doctor (GP) or local paediatrician for a blood test immediately.

Alteration in liver function – Both azathioprine and mycophenolate mofetil can affect your child's liver function. This should return to normal when your child stops taking the medicine. This will also be monitored by regular blood tests.

Upset stomach, nausea and vomiting – Both azathioprine and mycophenolate mofetil can make your child feel sick. These symptoms can be reduced by starting at a low dose and increasing it gradually over time. It may also help to give a smaller dose more frequently during the day. Please discuss this with your doctor, nurse or pharmacist.

Damage to the unborn baby – Both azathioprine and mycophenolate mofetil can affect the unborn baby. They must not be given to patients who may be pregnant or are likely to become pregnant in the near future. If your daughter is ten years old or older, we will ask her about her periods and any possibility she could be pregnant. If your daughter is sexually active, she must use a reliable form of contraception.

Azathioprine can also cause the following side effects:

Allergic reaction – Some people receiving azathioprine have an allergic reaction to the medicine. This reaction may be mild to severe. Signs of a mild allergic reaction include skin rashes and itching, high temperature, shivering, redness of the face, a feeling of dizziness or headache. If you see any of these signs, please report them to a doctor or nurse. Signs of a severe allergic reaction include any of the above, as well as shortness of breath. If you are in hospital and your child shows signs of a severe allergic reaction, call a doctor or nurse immediately. If you are at home and your child shows signs of a severe allergic reaction, call an ambulance immediately.

Mycophenolate Mofetil also causes the following side effects:

- Hair thinning or loss
- Convulsions (fits or seizures) very rarely

Interactions with other medicines

Some medicines can react with azathioprine and mycophenolate mofetil, altering how well they work. Always check with your doctor or pharmacist before giving your child any other medicine, including medicines on prescription from your family doctor (GP), medicines bought from a pharmacy (chemist) or any herbal or complementary medicines. The following medicines are known to interact with azathioprine or mycophenolate mofetil:

Azathioprine

- ACE inhibitors
- Allopurinol
- Antibacterial medicines especially co-trimoxazole and trimethoprim
- Anticoagulants
- Antiviral medicines

Mycophenolate mofetil

- Antacids
- Antibacterial medicines especially metronidazole, co-amoxiclav and rifampicin
- Antiviral medicines especially aciclovir

Important information

- Keep medicines in a safe place where children cannot reach them
- Keep the medicines in their original packaging at room temperature, away from bright light or direct sunlight and heat
- If your doctor decides that your child should stop taking these medicines or they pass their expiry date, please return to your pharmacist. Do not flush it down the toilet or throw it away.
- If you forget to give your child a dose and it is within a few hours of when the dose was due, give it as soon as you remember. Otherwise, do not give this dose but wait until the next dose was due. Do not give a double dose.
- Your child will need to have regular blood tests while taking these medicines. Initially, blood samples will need to be tested weekly for the first month then fortnightly for the next two months then monthly until you have been taking the medicine for six months. Blood tests will then be carried out every three to six months while your child's condition is stable.
- Your child should NOT have any live vaccines such as MMR, oral polio, chicken pox or BCG while taking these medicines. Inactivated or

- killed vaccines such as influenza/flu, meningitis C, pneumococcal infection, hepatitis, Hib, tetanus, diphtheria, whooping cough/ pertussis and the killed version of the polio immunisation are permitted if your child's condition is stable.
- If your child is taking these medicines and has not had chicken pox but then comes into contact with someone who has chicken pox or shingles (either face to face or longer than 15 minutes in the same room), you should report to your doctor immediately. Your child may be at risk of developing a more severe form of the infection and may need special treatment with immunoglobulin. If your child develops chicken pox or shingles, you should also report to your doctor immediately. If you are unsure whether your child has had chicken pox before starting these medicines, their immunity should be checked with a simple blood test at that time.

Useful numbers

- GOSH switchboard 020 7405 9200
- Pharmacy Medicines Information - 020 7829 8608 (Monday to Friday from 9am to 5pm)
- Clinical Nurse Specialist for Neuroimmunology - 020 7405 9200 extension 5051 or 0460

Compiled by the Neuroimmunology Centre and Pharmacy Department in collaboration with the Child and Family Information Group Great Ormond Street Hospital for Children NHS Foundation Trust, Great Ormond Street, London WC1N 3JH www.gosh.nhs.uk

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