

Paediatrics

Medicines, vaccinations, and travel with sickle cell disease

Medicines

Some medicines for people with sickle cell disease need to be given or monitored in hospital and will be prescribed in clinic. These may include:

- hydroxycarbamide (also called hydroxyurea)
- testosterone
- chelation agents, such as desferrioxamine (Desferal®)
- deferiprone (Ferriprox®)
- deferasirox (Exjade®)

If your child takes large doses of strong painkillers, such as opiates, these can only be prescribed by one provider, as per national guidance. All other medicines should be prescribed by your GP.

Children should take a preventative dose of penicillin V (penicillin prophylaxis) twice a day for life to reduce the risk of infection, illness, and death.

Penicillin is available as liquid or tablets. Liquid bottles expire after one week, so children are encouraged to take tablets as soon as possible. If liquid is needed, it is recommended to have 8 to 10 bottles on repeat prescription. The pharmacist can provide penicillin as a powder and show parents how to mix it with the right amount of water.



Patient Information

The doses of penicillin are:

- Up to 1 year - 62.5 mg twice a day
- 1 to 5 years - 125 mg twice a day
- 5 years and older - 250 mg twice a day

Your doctor may also recommend that your child takes folic acid. Folic acid is a vitamin that helps your body make healthy red blood cells. People with sickle cell disease may not have enough red blood cells because their bodies break them down faster (about 1 month) than people without sickle cell disease (about 3 months).

The doses of folic acid are 2.5 to 5mg daily.

Vaccinations

We recommend that your child has the vaccinations listed below, given by your GP. Please let us know when your child has received them so we can keep your hospital records up to date.

Some children may have missed some of the normal childhood vaccination schedule or may have been vaccinated abroad, where schedules can be different. Discuss this with your GP so your child can catch up on any missed vaccinations.

Recommended vaccinations:

- Normal childhood vaccination schedule
- Pneumovax (from 2 years old, then every 5 years)
- Haemophilus influenzae type B (Hib) vaccine
- Meningococcal ACWY vaccine
- Meningococcal B vaccine (newly available)
- BCG
- Annual flu vaccine

Patient Information

Travel

Travel can increase the risk of problems (crises) due to blood clots (thrombosis), infection, extreme tiredness (fatigue), dehydration and change in climate.

Air travel

- Tell the airline that your child has sickle cell anaemia.
- Encourage your child to walk around at least every 30 minutes and drink plenty of fluids during the flight.
- If your child is well and the cabin is pressurised cabin, extra oxygen is not usually needed.
- Air travel can increase the risk of blood blockage in the spleen (splenic infarct). Your doctor should be consulted if your child has pain in the left upper part of their tummy (abdomen).

Overland travel

- Make sure your child has plenty of breaks to move around and that they have plenty to drink.
- Make sure they get enough rest to avoid becoming too tired.

Antibiotics

- Your child should continue their regular penicillin or an equivalent, such as erythromycin if allergic to penicillin.
- Ask your GP for a treatment course of antibiotics to take with you in case they are needed whilst you are travelling.
- If your child becomes seriously unwell while away, they must see a doctor promptly.
- Seek early treatment for dog bites, tick bites, or other infections. Children with sickle cell disease have a spleen that does not work as well, making them more prone to infections, although this risk is reduced by vaccinations and penicillin.

Patient Information

Travel vaccinations

Make sure your child has all routine vaccinations recommended for the country you are travelling to. National guidance can be found on the UK government website: www.gov.uk.

Malaria

- People with sickle cell disease are at risk of malaria, even if they have lived in a malarial area or travel there regularly. Malaria can be life-threatening for people with sickle cell disease.
- Your child should wear protective clothing, use insect repellent and mosquito nets, and take malaria prevention tablets.
- Your child may need to start malaria tablets a little earlier than usual so side effects can be monitored. Take malaria treatment medicines with you if you will be far from medical care.
- Know your child's G6PD status, as some medicines can cause problems in people with low G6PD levels.

Insurance

- Make sure you have travel insurance that covers all costs, including bringing your child back to the UK if they become ill during your holiday.
- You must declare that your child has sickle cell disease, or the insurance will be invalid.
- The Sickle Cell Society may be able to recommend suitable insurers.

Where can you get more information?

The Sickle Cell Society

54 Station Rd, London, NW10 4UA

Tel: 020 8961 7795

Website: www.sicklecellsociety.org

The UK Thalassaemia Society

19 The Broadway, London, N14 6PH

Tel: 020 8882 0011

Website: www.ukts.org

Patient Information

NHS Sickle Cell and Thalassaemia Screening Programme

www.gov.uk/topic/population-screening-programmes/sickle-cell-thalassaemia

Contacts

Paediatric consultants

Dr Muhammad Farooqi and Dr Kim Neuling

Secretary: 024 7696 7234

Paediatric ANP for Haematology and Oncology

Kate Norton

Tel: 024 7696 7291

Paediatric Haemoglobinopathy clinical nurse specialists

Vicki Hagger and Elle Lakhani

Service hours: 8am – 5pm, (Monday - Friday)

Secretary: 024 7696 7234

Office: 024 7696 7225

Mobile: 07876681069

Please note: the nursing team is available for advice and guidance only. This is not an emergency contact number. Please allow up to 2 working days for a response.

The Trust has access to interpreting and translation services. If you need this information in another language or format, please contact and we will do our best to meet your needs. Please contact the secretary on 024 7696 7234.

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