Medications, vaccinations and travel in sickle cell disease

North Central London Haemoglobinopathy Network jointly with Whittington Health, Royal Free London and Luton and Dunstable NHS Foundation Trust

Joint Red Cell Unit
If you need a large print, audio or translated copy of the document, please contact us on 020 3447 9638. We will try our best to meet your needs.

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Medications

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

- hydroxycarbamide
- testosterone
- chelation agents, such as desferrioxamine (Desferal®)
- deferiprone (Ferriprox®), and
- deferasirox (EXJADE®).

If you take large doses of strong painkillers, such as opiates, they will need to be prescribed from one place only (which may be clinic), as part of national guidance. Other medications should be prescribed by your GP.

If you had your spleen removed, you should take a preventative dose of penicillin V (penicillin prophylaxis) twice a day for the rest of your life to reduce the risk of illness and death. This is available in a liquid and tablet form. The bottles of liquid expire after one week, so we encourage children to learn how to take tablets as soon as it is possible. If liquid is needed, we recommended that the repeat prescription be for eight to 10 bottles. The pharmacist should dispense it as a powder and teach the parents to make it up with the required amount of water.

The doses of penicillin are:

<table>
<thead>
<tr>
<th>Age</th>
<th>Dose</th>
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<tbody>
<tr>
<td>Up to one year of age</td>
<td>62.5 mg twice a day</td>
</tr>
<tr>
<td>One to four years of age</td>
<td>125 mg twice a day</td>
</tr>
<tr>
<td>Five years old and over</td>
<td>250 mg twice a day</td>
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</tbody>
</table>
Your doctor may also recommend that you take folic acid. Folic acid is a B vitamin that is important when making new cells and that patients with sickle cell disease may become deficient in. This is because their red blood cells may last less than a month, compared to three months in people without a haemoglobin disorder.

**The doses of folic acid are:**

<table>
<thead>
<tr>
<th>Age</th>
<th>Dose</th>
</tr>
</thead>
<tbody>
<tr>
<td>One month to four years old</td>
<td>2.5 mg once a day</td>
</tr>
<tr>
<td>Five years old or over</td>
<td>5 mg once a day</td>
</tr>
</tbody>
</table>

**Vaccinations**

The vaccinations listed below are recommended and should be administered at your GP surgery. We ask you to tell us when you have had them so that we can keep your hospital records up to date.

We know that some adults may have missed the normal childhood vaccination schedule or may have been vaccinated abroad where the schedule may have been different. You should discuss this with your GP so that they can bring you up to date with any vaccinations you may have missed.

- Normal childhood vaccination schedule
- Hepatitis B vaccination (from one year of age)
- Pneumovax (from two years of age and then every five years)
- Haemophilus influenzae type B (Hib) vaccine
- Meningococcal ACWY vaccine
- Meningococcal B vaccine (newly available)
- BCG
- Annual influenza.
Travel

Travel can lead to an increased risk of crises due to thrombosis (blood clots), infection, fatigue (extreme tiredness), dehydration and climate change.

Air travel

• Keep mobile (walk around at least every half hour) and well-hydrated, and avoid alcohol.

• If you are well and in a pressurised cabin, you will not need extra oxygen.

• There is a possible increased risk of splenic infarct (blood blockage in the spleen) from air travel, and this should be considered by your doctor if you have pain in the left upper part of your abdomen.

Overland travel

• Keep mobile and well-hydrated, and avoid fatigue.

Antibiotics

• Take your regular penicillin or equivalent (such as erythromycin) if you are allergic to penicillin.

• Ask your GP for a treatment course of antibiotics in case you need them. However, if you are truly unwell when you are away, you will need to see a doctor.

• Seek treatment for dog bites and tick bites.

• Seek early treatment for other infections. Remember that if you have sickle cell disease, your spleen does not work well and therefore you are more prone to infections. This risk is reduced with vaccinations and your penicillin but it is not eliminated.

Travel vaccinations

Please get all the routine vaccinations as recommended for your area of travel, for example meningococcal ACWY and hepatitis A vaccine if travelling to an area of increased risk of infection.
Malaria
• People with sickle cell are at risk of malaria, even if they were previously resident in a malarial area or return there regularly. Malaria in sickle cell can be life-threatening.

• It is important to wear protective clothing, insect repellent, mosquito nets and to take malaria prevention tablets. You may need to start the medicine a little earlier than recommended to check that you are not having any side effects.

• Take medicines used to treat malaria with you if you are staying far from medical care.

• You should be aware of your G6PD status as some medications may cause problems in those with G6PD deficiency.

Insurance
• Get travel insurance that covers costs for bringing you back to the UK if you were to fall ill. You need to declare your sickle cell disease or your insurance will be invalid. The Sickle Cell Society may be able to recommend insurers.
Contact details

Haematology advice line (office hours, children and adults):
020 3447 7359

Adult haematology advice line (out of hours):
07852 220 900

Paediatric helpline (out of hours):
• nurse in charge 07961 081 645
• ward T11S 020 3456 7890 ext. 71103 or 71143

Apheresis:
020 3447 1803

Website: www.uclh.nhs.uk/JRCU

Haematology consultants:
Professor John Porter
Dr Sara Trompeter
Dr Perla Eleftheriou
Dr Bernard Davis
Dr Farrukh Shah

Specialist nurses:
Bernadette Hylton (adults)
Nancy Huntley (apheresis)
Catherine Mkandawire (children)
Where can I get more information?

The Sickle Cell Society
Tel: 020 8861 7795
Website: www.sicklecellsociety.org

NHS Sickle Cell and Thalassaemia Screening Programme
Website: www.gov.uk/guidance/sickle-cell-and-thalassaemia-screening-programme-overview

The UK Thalassaemia Society
Tel: 020 8882 0011
Fax: 020 8882 8618
Email: office@ukts.org
Website: www.ukts.org

UCL Hospitals cannot accept responsibility for information provided by external organisations.