

Medications, vaccinations and travel with thalassaemia

Information for parents

Medications

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

- hydroxycarbamide (also known as hydroxyurea)
- testosterone
- chelation agents, such as desferrioxamine (Desferal[®])
- deferiprone (Ferriprox[®]), and
- deferasirox (Exjade[®]).

If your child takes 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 your child has had their spleen removed, they should take a preventative dose of penicillin V (penicillin prophylaxis) twice a day for the rest of their 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 recommend that the repeat prescription be for eight to 10 bottles. The pharmacist should dispense it as a powder and teach parents to make it up with the required amount of water.

The doses of penicillin are:

Up to one year of age	62.5 mg twice a day
One to four years of age	125 mg twice a day
Five years old and over	250 mg twice a day

Your doctor may also recommend that your child takes folic acid. Folic acid is a B vitamin that is important when making new cells and which patients with thalassaemia 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:

One month to four years old	2.5 mg once a day
Five years old or over	5 mg once a day

Vaccinations

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

We know that some children 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 your child up to date with any vaccinations they may have missed.

- Normal childhood vaccination schedule
- Hepatitis B vaccination (from one year of age)
- BCG
- Annual influenza

If your spleen has been removed, you also need:

- 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)

Travel

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

Air travel

- Keep your child mobile (walk around at least every half hour) and well-hydrated. Avoid alcohol.
- If your child is well and in a pressurised cabin, they 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 your child has pain in the left upper part of your abdomen.

Overland travel

Keep your child mobile and well-hydrated, and avoid fatigue.

Antibiotics

- Your child should take their regular penicillin or equivalent (such as erythromycin) if they are allergic to penicillin.

- Ask your GP for a treatment course of antibiotics in case your child needs them. However, if your child is truly unwell when you are away, they will need to see a doctor.
- Seek early treatment for dog bites and tick bites.
- Seek early treatment for other infections. Remember that if your child has thalassaemia, their spleen does not work well and therefore they are more prone to infections. This risk is reduced with vaccinations and penicillin but it is not eliminated.

Travel vaccinations

Please get all the routine vaccinations for your child as recommended for your area of travel, for example meningococcal ACW Y and hepatitis A vaccine if travelling to an area of increased risk of infection.

Malaria

- People with thalassaemia are at risk of malaria, even if they were previously resident in a malarial area or return there regularly. Malaria in thalassaemia can be life-threatening.
- It is important that your child wears protective clothing, insect repellent, uses mosquito nets and takes malaria prevention tablets. Your child may need to start the medicine a little earlier than recommended to check that they 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 child's G6PD status as some medications may cause problems in those with G6PD deficiency.

Insurance

Get travel insurance that covers costs for bringing you and your child back to the UK if they were to fall ill. You need to declare their thalassaemia or their insurance will be invalid. The UK Thalassaemia Society may be able to recommend insurers.

Contacts

Specialist nurses

Emma Prescott (nurse specialist, thalassaemia)	020 7288 5225
Matty Asante-Owusu (community matron, adults)	07920 711210
Edith Aimiwu (nurse specialist, children)	07799 347161

Haematology consultants

Dr Bernard Davis
 Dr Farrukh Shah
 Dr Ali Rismani

Paediatric consultants

Dr Andrew Robins
 Dr Sara Hamilton

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Where can I get more information?

The UK Thalassaemia Society

19 The Broadway,
London N14 6PH

Tel: 020 8882 0011

Website: www.ukts.org

The Sickle Cell Society

54 Station Rd, London NW10 4UA

Tel: 020 8861 7795

Website: www.sicklecellsociety.org

Red Cells R Us

Sickle Cell & Thalassaemia Centre

17a Hornsey Street

London N7 8GG

020 3316 8853/8854

Twitter: @Red Cells R Us

Facebook: Red Cells R Us

Google+: Red Cells R Us (in community section)

NHS Sickle Cell and Thalassaemia Screening Programme

<https://www.gov.uk/topic/population-screening-programmes/sickle-cell-thalassaemia>

Patient advice and liaison service (PALS)

If you have a question, compliment, comment or concern please contact our PALS team on 020 7288 5551 or whh-tr.whitthealthPALS@nhs.net

If you need a large print, audio or translated copy of this leaflet please contact us on 020 7288 3081. We will try our best to meet your needs.

Healthwatch England

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