



Medications, vaccinations and travel with thalassaemia

A patient's guide

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[®])
 - 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 antibiotics for adults 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 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 you take 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



Immunisations (Vaccines)

- The immunisations 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 immunisation schedule or may have been immunised 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 immunisations you may have missed.
 - Normal childhood immunisation schedule
 - Hepatitis B immunisation (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) immunisation
 - Meningococcal ACWY vaccine
 - Meningococcal B vaccine

Travel

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

Air travel

- Keep mobile (walk around at least every half hour).
- Keep well-hydrated.
- Avoid alcohol.
- If you are well and in a pressurised cabin, you will not need extra oxygen.

Overland travel

- Keep mobile.
- Keep well-hydrated.
- 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 early treatment for dog bites and tick bites.
- Seek early treatment for other infections.

Travel vaccinations

- Please get all the routine vaccinations 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. Malaria in thalassaemia 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 thalassaemia, or your insurance will be invalid. The UK Thalassaemia Society may be able to recommend insurers.

Contact details

- Your consultant team is:

Dr Emma Drasar
 Dr Ryan Mullally
 Dr Ana Ortuno-Cabrero
 Dr Ali Rismani
 Dr Zara Sayar
 Dr Annabel McMillan
 Dr Prabal Mittal
 Dr Janine Younis

- Adult departmental contacts:

whh-tr.haematologyteam@nhs.net Haematology Administration Team

whh-tr.adultsicklecons@nhs.net Adult Sickle Cell Clinical Nurse Specialist (CNS) team

ncl.redcellteam@nhs.net Community link (Sickle cell, Thalassaemia and Rare Anaemia)
 0203 316 8853 Community phone number

emma.prescott@nhs.net Whittington Thalassaemia CNS

niamh.malone-cooke@nhs.net Whittington Thalassaemia CNS

- Network website:

<https://www.uclh.nhs.uk/theredcellnetwork/subscribe>

If you or your family have any other questions, please do not hesitate to contact any of the above medical team at Whittington Health.



Where can I get more information?

The Sickle Cell Society

54 Station Rd, London NW10 4UA

Tel: 020 8861 7795

Website: www.sicklecellsociety.org

The UK Thalassaemia Society

19 The Broadway, London N14 6PH

Tel: 020 8882 0011

Website: www.ukts.org

Red Cells R Us

Sickle Cell & Thalassaemia Centre

17a Hornsey Street, London N7 8GG

Tel: 020 3316 8853/8854

Twitter: @Red Cells R Us

Facebook: Red Cells R Us

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

Patient advice and liaison service (PALS)

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

If you need a large print, audio or translated copy of this leaflet please email whh-tr.patient-information@nhs.net. We will try our best to meet your needs.

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