



# Medications, vaccinations and travel with sickle cell disease

# A patient's guide

# **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 (also known as hydroxyurea)
  - > testosterone
  - chelation agents, such as desferrioxamine (Desferal<sup>®</sup>)
  - deferiprone (Ferriprox<sup>®</sup>)
  - deferasirox (Exjade<sup>®</sup>)
- 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 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 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:

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 given 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 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
  - ➢ BCG
  - Annual influenza.

### **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 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.
- 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.
- 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. 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 ACW Y 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**

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.adultsicklecns@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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