Living with sickle cell disease

Information and advice for patients

Sickle Cell and Thalassaemia

As someone with sickle cell disease it is important to learn as much as possible about your condition so you know how to keep well and avoid things that can cause a sickle cell crisis. The triggers for a crisis include:

- Dehydration
- Not having your recommended medications and vaccinations
- Being too cold or too hot
- Excessive physical exertion/stress
- Emotional stress and anxiety
- Not eating a healthy diet
- Other illnesses or infections

How you can avoid the triggers for a sickle cell crisis

Keep hydrated
You can become dehydrated if you are not drinking enough fluids, especially on a hot day, or if you have diarrhoea and/or vomiting.

To keep hydrated:

- Drink 3-4 litres of fluid per day in the form of juice, squash or water.
- Only have tea and coffee in moderation as they increase the amount of urine you pass.
- Only drink alcohol in moderation as it can cause dehydration.

If you are unable to drink sufficient fluids because you are vomiting, please contact the Sickle Cell and Thalassaemia (SCAT) centre for advice.

Have your recommended medications and vaccinations
If you have been prescribed medications it is important to take these as directed. You are also advised to take the following:

Folic acid
Folic acid is needed to help your body make red blood cells. A normal balanced diet should contain adequate folic acid but it is recommended that you take a 5mg supplement of folic acid each day.

Living with sickle cell disease

Information and advice for patients

Sickle Cell and Thalassaemia

Penicillin V

People with sickle cell disease have a spleen that doesn't work properly. The spleen is a gland in the abdomen (tummy) and is part of the immune system which helps the body to fight infections. If your spleen isn't working properly you will be more prone to developing infections, particularly from certain types of bacteria, including pneumococcus bacteria.

To reduce the risk of developing an infection you should take 250mg of Penicillin twice a day (adults only) or 250mg of Erythromycin twice a day if you allergic to penicillin. You can find further information about these medications, including the possible side effects, in the manufacturer's leaflet that comes with them. It is also important that you know the warning signs of an infection so that you can seek help quickly. Your specialist nurse or doctor will give you more information about these.

Vaccinations

You should have had all the immunisations in the childhood immunisation programme and should continue to have the following booster doses:

- **Pneumovax** - every 5 years to protect against the pneumococcus bacteria.
- **Meningivac** - This gives protection against meningococcus types A and C which cause meningitis.
- **Influenza (flu)** - once a year to protect against the flu virus.
- **Hepatitis B** – this is transmitted through infected blood and sexual contact with an infected person.

You can get these vaccinations from your GP/Practice Nurse.

Avoid getting too hot or cold

Extremes of temperature can trigger a sickle cell crisis. To avoid this make sure you wrap up warm in cold weather and try to keep cool in hot weather and drink plenty of fluids to make sure you keep hydrated.

Avoid excessive physical stress

It is important that you exercise regularly, but make sure you only exercise within your limits. Excessive exercise can trigger a sickle
cell crisis.

Avoid emotional stress and anxiety

If you feel stressed or are finding it difficult to cope with the various challenges of work, relationships, finances etc. please talk to your specialist nurse, doctor, social worker or psychologist about this. It is important that you get the support you need to reduce emotional stress and anxiety.

Living with sickle cell disease

Information and advice for patients

Sickle Cell and Thalassaemia

Eat a healthy diet
Like anyone else, you should eat a healthy, balanced diet with plenty of fresh fruit and vegetables (these contain folic acid among other nutrients). Please do not take any iron supplements without talking to your specialist nurse or doctor first.

Travel advice

Travelling with sickle cell disorder is not usually a problem but it is important to plan your trip carefully. Before travelling abroad you will need to get a letter from the SCAT centre with the following information:

- The type of sickle cell disease you have
- Any complications you have
- The medications you are taking
- Contact details for your SCAT team at home

Ensure you take a sufficient amount of medication on holiday with you as some pain medications may be difficult to get abroad. You also need to check whether you need to have any extra vaccines before you travel or take any extra medications such as anti-malaria tablets. It is also vital that you get adequate travel insurance that will cover you if you have any medical problems related to your sickle cell disease whilst abroad.

If you are travelling by plane, make sure you drink plenty of non-alcoholic fluids, keep warm and go for short frequent walks up and down the aisle if your journey is long. Whilst abroad it is important that you keep hydrated; if you are not sure about the cleanliness of the water then drink bottled water, particularly if you develop diarrhoea and/or vomiting.

Contact details

If you have any questions or concerns please contact the Sickle Cell and Thalassaemia Centre.

Sickle Cell & Thalassaemia Centre
Sandwell & West Birmingham NHS Trust
City Hospital
Dudley Road
Birmingham
B18 7QH

Tel: 0121 507 6040
Monday 9am – 4pm
Tuesday 9am – 6pm
Wednesday, Thursday and Friday 9am – 5pm

Living with sickle cell disease

Information and advice for patients

Sickle Cell and Thalassaemia

For Further information

You can find more information about sickle cell from the Sickle Cell Society: *www.sicklecellsociety.org* (Accessed 23 July 2020).

For more information about health whilst travelling abroad visit the Fit for Travel website: *www.fitfortravel.nhs.uk* (Accessed 23 July 2020).

For more information about our hospitals and services please see our websites *www.swbh.nhs.uk*, follow us on Twitter *@SWBHnhs* and like us on Facebook *www.facebook.com/SWBHnhs*.

Sources used for the information in this leaflet

Sickle Cell Society (2018) Standards for the clinical care of adults with sickle cell disease in the UK. Available at: https://www.sicklecellsociety.org/wp-content/uploads/2018/05/Standards-for-the-Clinical-Care-of-Adults-with-Sickle-Cell-in-the-UK-2018.pdf (Accessed 23 July 2020).

If you would like to suggest any amendments or improvements to this leaflet please contact SWB Library Services on ext 3587 or email *swbh.library@nhs.net*.

Health & care information you can trust
The Information Standard Certified Member

A Teaching Trust of The University of Birmingham
Incorporating City, Sandwell and Rowley Regis Hospitals

ML6215
Issue Date October 2020
Review Date: October 2023