NHS
Sandwell and West Birmingham
NHS Trust

Moving from child to adult services: a guide for Sickle Cell Disease

Information and advice for young people

Sickle Cell and Thalassaemia Centre, Midland Metropolitan University Hospital (MMUH)

What will happen when I move from child to adult sickle cell services?

When you move over from child services you will be under the care of the Sickle Cell and Thalassaemia centre (SCAT). This is located at MMUH.

The service holds quarterly transition evenings for patient and families to come and look around the service and meet some of the staff.

You might have already met some of the nurses and doctors at joint transition clinics at your child services.

When you are ready to start at the adult service you will be given an appointment with the doctors. These will be the doctors who will take over your care when you move over to the adult service. You will receive the appointment letter via post.

After this appointment you will be able to access the services the centre offers for individuals living with Sickle Cell and Thalassaemia.

What services are available at SCAT?

Clinic appointments

These are planned appointments that will be posted to your home. When you first move to our service you may find you have a few appointments close together. This is so we can get to know you and set up an agreed plan of care. Once you have settled in, these appointments will fall into a regular routine based on your needs.

If you have been unwell, we may need to see you more regularly for a period of time, or if you feel you need to be seen sooner you can ring the centre (the contact number of the centre is at the end of this leaflet) and discuss this with a member of the nursing team.

Elective blood transfusions

Some people with sickle cell need to have regular blood transfusions. The centre will be made aware when you come for your first appointment if you require regular blood transfusions. At your first appointment, we will book you in for your first transfusion and we will take some blood samples. After your first blood transfusion, the nursing staff will book future appointments with you in the centre.

We offer advice, education and support for patients who have a central line (Hickman line, Groshong line, PICC) or portacath in place. Chelation refers to medications you take to prevent iron build-up in your body as a result of regular transfusion therapy. We will help and support you with understanding your Chelation regime.

The SCAT centre will supply you with any equipment you need for your central line/portacath care and your chelation therapy.

Day case pain management

Each patient has their own pain management care plan for at home and this is important to enable you to get on with life.

We understand that people would rather not be admitted into hospital when they are unwell; so we offer a day case management service. If you suffer from sickle cell disease and you have a day where you find your usual management plan is not working, you can come in for the day and be seen and treated by members of our team.

We aim to help you manage your condition during the day so that by the time we shut you can go home feeling better without having to be admitted into hospital. Many of our patients find this service invaluable especially if they are working or studying. If you do need to come and see us, we ask that you come as early as you can so we can deliver the optimum treatment to you. We open Monday 9am to 4 pm and Tuesday to Friday 9am to 5pm.

Prescriptions

Some medications can only be prescribed by the hospital, such as hydroxycarbamide or chelation therapy. If you are on these medications, then you will need to request these from the SCaT team using the email address **swbh.scat-prescriptions@nhs.net**. When the prescription is ready, you will be able to collect this from the SCaT Centre. Prescription requests should be emailed to **swbh.scat-prescriptions@nhs.net**. Please allow a minimum of 2 days notice (weekdays) before your prescription will be available. All other medication that you may be on, such as penicillin or folic acid, should be prescribed by your GP. You will need to find out from your GP surgery how to request these.

Once you are over 18, you may have to pay for your prescriptions. Some patients may be eligible for free prescriptions. You can check if you meet the criteria for free prescriptions on the NHS Business Services Authority website (**https://www.nhsbsa.nhs.uk/check-if-you-have-nhs-exemption**). If you are not exempt but on a low income, then you may be able to seek help under the NHS Low Income Scheme (**https://www.nhsbsa.nhs.uk/nhs-low-income-scheme**). For people who have to pay NHS prescription charges and need lts of prescritption items, then it may be possible to save money with a prescription payment certificate (PPC). More information about PPC can be found on the NHS BSA website (**https://www.nhsbsa.nhs.uk/help-nhs-prescription-costs/nhs-prescription-prepayment-certificate-ppc**). Talk to your local pharmacist or GP for futher information about prescription charges.

Some medications such as hydroxycarbamide might require regular blood tests. These appointments can be made via the doctors or nurses at your SCAT clinic appointment. Make sure you do not miss these appointments to ensure your prescriptions continue without problems. If you start to develop any side effects or symptoms to a new medication or any medication please ring the centre straight away and speak to a member of staff.

Is there anything I need to do?

Now you are moving to adult services, it is important you understand your condition and how to take care of yourself and what to do if there is a problem.

Relationships: If you have a boyfriend or girlfriend and are thinking about a sexual relationship, it is a good idea to start thinking about contraception. This is because if you have sickle cell disease, any children you have may also have the condition as it's passed through the genes.

It is very important to think about contraception if you are a female, because women with sickle cell disease can develop complications in pregnancy and need extra care. Most forms of contraception are suitable for young people with sickle cell disease, your GP or Nurse can give you advice on this. There is also lots of NHS health centres in Birmingham where you can get advice, see Birmingham sexual health services at the end of this leaflet.

Stress and pain: Most of the time we hope you will feel happy and healthy and supported, but there will always be times when living with a long term condition and juggling life can get on top of you. Stress is something we try not to think about too much on a day to day basis but it is a factor that can make us feel poorly and this can be especially true if you have sickle cell. It is a good idea to try and adopt some good stress relieving strategies to combat this. Simple things can help such as:

- A relaxing bath
- Gentle sport-yoga for example
- Reading/listening to music
- Massages or therapies
- Meditation
- Socialising

It's also a good idea to think of some things that will help with distraction when you are having a painful crisis.

Some of our patients find the following helpful when they are feeling unwell:

- Chatting on the phone
- Sleeping
- Knitting/sewing
- Playing computer games/apps on phone
- Reading
- Listening to music

Please note: Distraction techniques help manage pain alongside treatment so please still take medications you need as well.

Feeling blue: Sometimes having a long term condition can get you down or seem unfair. If you are finding it hard and need someone to talk to or worried you might be depressed, why not try the following:

- Speak to the nurses or doctors when you are at the sickle cell centre
- Make an appointment with your GP or practice nurse. Speak to a close friend or family member you trust

There are also other organisations that offer support, there are contact details at the end of this leaflet.

Don’t be afraid to ask for support from your adult service if you need it. Remember that services you access are always going to be private and confidential.

Living healthy: Eating a well-balanced diet which includes vegetables and fruit is important. Some vitamin deficiencies can make you feel unwell so it’s important to eat well. Ask your GP about health advisor services/health exchange if you would like to learn more about nutrition and eating well. There is also information available online.

Having sickle cell disease means it is important not to get dehydrated as this can start a painful crisis. Drink plenty of fluids every day to keep your self-hydrated; fluids like water, squash and juices are great. Try to limit carbonated drinks that are high in caffeine and sugar and hot drinks like tea and coffee as they do not offer effective hydration. Swap for healthier options such as green or fruit teas or caffeine free options.

Gentle exercise is important for keeping fit and healthy, please ask if you want any advice.

Always seek advice before taking any supplements as some are not suitable if you are on certain treatments such as iron overload medication.

Having sickle cell disease puts you at a greater risk of becoming unwell if you pick up certain infections. It is important to have your vaccinations and we particularly recommend you have the following:

- Flu Vaccine every year
- Pneumococcal vaccine every five years. This protects you against a type of pneumonia.

You may need to check with your GP when you last had these vaccines.

What should I do if I am unwell?

If you are having a sickle cell crisis there are things you can do at home first to make yourself feel better.

Start by resting and keeping yourself warm and comfortable. Tell others around you are not feeling well so they can support you. Drink plenty and eat what you can. Try your usual pain management techniques such as hot water bottles or heat rubs on the site of pain. Most of you will have a plan of what medication to take at home if you feel unwell, below is a typical example of one:

1. Start by taking paracetamol - Four times per day.
2. If this doesn’t help, you can try adding in Ibuprofen (these are known as non-steroidal anti-inflammatory painkillers), this can be taken three times a day but you should eat something if you are taking this medication as it can upset your stomach. If you have asthma, kidney or stomach problems, discuss with your doctor before taking this medication.
3. If you are still in pain you can add in codeine or dihydrocodeine, which is stronger, four times a day. You might have a paracetamol and codeine mixture (known as co-codamol) that you could take instead of paracetamol. If you are still in pain and not managing after this, we would advise you to contact the SCAT centre as you may require stronger medication in hospital.

When to seek medical advice?

You should seek medical advice from your GP, nurse or SCAT when you experience the following conditions:

- Severe sickle cell painful crisis that is not resolving
- High temperatures, over 38°c
- Uncontrollable shivering
- Coughing up sputum and persistent coughs
- Smelly cloudy urine
- Burning when passing urine
- Priapism
- Shortness of breath
- Chest pain
- Symptoms of stroke (Dial 999 if you have any of these symptoms):
  - Your face has dropped on one side
  - You find it hard to speak or slurring your words
  - You cannot lift both of your arms and keep them there

It is important that you get help quickly if you are unwell as people with sickle cell disease can become unwell very quickly.

In an emergency or outside SCAT opening hours, you should attend your nearest emergency department.

Further questions?

If you still have any questions about sickle cell disease, your treatment or living with the condition you can call the SCAT centre to chat to one of the team. You can also drop by to speak to us too.

The SCAT centre contact details:

Sickle cell and Thalassaemia centre
C3, 3rd Floor
Midland Metropolitan University Hospital (MMUH)
Grove Lane
Smethwick
B66 2QT

Tel:0121507 6040

Opening hours
Tuesday, 9am – 6pm
Monday, Wednesday, Thursday 9am – 5pm
Friday, 9am – 4pm
Saturday blood transfusion service only

We also have a Facebook page with the name Scatbham (Please note: this is a social site and shouldn't be used to seek medical advice).

Further information

There are other organisations that can help support you with your condition:

Wolverhampton Sickle cell care and social activities centre

Chancel Court
Bilston
WV14 6AA

Telephone: 01902 498 274

The Wolverhampton service offers a range of counselling and therapeutic services to help support individuals manage their conditions, including alternative therapies such as massage.

OSCAR

Organisation for Sickle cell and anaemia research and Thalassaemia support (OSCAR)

Birmingham: **www.oscarbirmingham.org.uk**

Sandwell: **www.oscarsandwell.org.uk**

Birmingham sexual health services

This website has links to lots of clinics that offer various services such as contraception advice, family planning, and sexual health testing.

https://umbrellahealth.co.uk/#

Telephone: 0121 237 5700

Whittal street Birmingham B4 6DH

Or

Boots, 66 High Street B4 7TA

Birmingham Healthy Minds

https://www.bsmhft.nhs.uk/our-services/birmingham-healthy-minds/

Telephone: 0121 301 2525

Sickle cell society

Telephone: 020 8961 8346

www.sicklecellsociety.org

NHS Website

https://www.nhs.uk/conditions/sickle-cell-disease/

(All websites accessed 06 September 2024).

The Sickle Cell and Thalassaemia centre have lots of patient information leaflets so feel free to browse and help yourself when you are visiting.

More information about our hospital services please visit our website **www.swbh.nhs.uk** you can also follow us on X **@SWBHnhs** and like us on facebook **www.facebook.com/SWBHnhs**.

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

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