

Moving from child to adult services: A guide for Thalassaemia patients

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 Thalassaemia 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 Midland Metropolitan University Hospital (MMUH).

The service holds quarterly transition evenings for patients 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 in the 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 the planned consultant 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 a 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 and discuss this with a member of the nursing team (the contact number for the centre is at the end of this leaflet).

Elective blood transfusions

Some people with thalassaemia will be on 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 transfusion appointments with you in the centre. We do offer a Saturday transfusion service for some patients, please mention if you would be interested in discussing this option.

Chelation refers to the medications you take everyday to prevent iron overload in your body as a result of regular blood transfusion therapy.

We will help and support you with understanding your Chelation regime. Your chelation regime may be in the form on tablets or an infusion. We have more information available on both these approaches.

We offer advice, education and support for patients who have a central venous access device in place. Hickman® line, Groshong® line, PICC (peripherally inserted central catheter) or portacath (an implanted port) are all types of central venous access devices.

The SCAT centre will supply you with the equipment you need for your central venous access device care and chelation therapy.

We want you to have the knowledge and tools to manage your condition and treatment as independently as possible.

Feeling unwell

All of us at some time will feel unwell. When this happens we usually go to see our local GP. This should continue to be the case for you unless you are concerned the symptoms are related to thalassaemia. In this circumstance we may need to see you at the centre. This is because there are some complications associated with thalassaemia that can make you very unwell quickly. For this you may require specialist treatment from your haematology doctors and nurses.

When to call us

You can call us any time to discuss your care, however there are some times it will be particularly important to get in touch.

Infections

If you have a central venous access device inserted, you could be at risk of infection. Please call us if you experience the following symptoms:

- high temperature, you may feel very cold and shaky
- fatigue and tiredness
- nausea and vomiting
- itching, redness, swelling or leaking from the insertion site of the line.

If these symptoms occur outside the SCAT opening hours you should present without delay to the emergency department and inform them that you have a central venous access device in place.

Anaemia

Because in thalassaemia your body struggles to make enough red blood cells even with transfusions you may still feel anaemic and require a transfusion sooner. Please call us if you experience the following symptoms

- feeling dizzy, light-headed or faint
- heart racing or beating hard in your chest (or a fluttery feeling)
- shortness of breath, particularly when exercising

- pale skin
- tiredness and loss of energy
- leg cramps, ache in bones
- difficulties sleeping and headaches

Iron overload

Regular blood transfusions can cause a build up of iron in your body. You may remember your doctor discussing ferritin levels with you in previous clinic appointments. You will be on a chelation medication to help remove this excess iron from your body and keep you healthy.

If you don't take chelation the iron will build up. High levels of iron in your body can be very dangerous and cause complications with your heart, liver and other organs of the body. The centre will work closely with you to ensure you know what to take and when, to keep yourself healthy.

However if you experience any of the following you must contact the sickle cell and thalassaemia centre or an emergency department immediately:

- chest pain
- very rapid heart beat
- shortness of breath
- coughing up pink or blood stained sputum
- yellowing of the skin and whites in the eyes
- swollen abdominal
- unusual bruising

Prescriptions

Some medications can only be prescribed by the hospital, such as 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 lots of prescription 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 further information about prescription charges.

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 partner and are thinking about a sexual relationship, it is a good idea to start thinking about contraception. This is because if you have thalassaemia any children you have may also have the condition as it's passed through the genes. Pregnancy can also put extra strain on your body if you have thalassaemia, if you suspect you may be pregnant please ring the centre to book an appointment to see one of the doctors so we can arrange extra support for you through this time.

Your GP or Nurse can give you advice on contraception and family planning. There are also NHS health centres in Birmingham where you can get advice.

Sometimes with thalassaemia you may find that growth and puberty can be delayed. You may be seen in an endocrine clinic for this and receive specialist hormone treatment. These clinics will continue at your adult service.

If you are thinking of starting a family now or in the future and are worried about issues surrounding fertility it is important to let the nurses and doctors at the centre know so we can address these concerns in clinic appointments. We will be able to give you advice.

Stress

We hope you will feel happy and healthy and supported most of the time, 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 most people don't think about too much on a day to day basis, but it is a factor worth considering. If you think you are stressed it is a good idea to try and adopt some good stress relieving strategies to combat this when things are tough. Simple things can help such as:

- relaxing bath
- gentle sport-yoga for example
- reading/listening to music
- massages or therapies
- meditation
- socialising

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, try the following:

- speaking to the nurses or doctors when you are at the sickle cell and thalassaemia centre
- make an appointment with your GP or practice nurse
- speak to a close friend or family member you trust

There are other organisations that offer support; 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. Drink plenty of fluids everyday to keep yourself 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 benefit hydration. Swap for healthier options such as green and 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 thalassaemia 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:

1. Flu Vaccine every year
2. Pneumococcal vaccine every 5 years

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

When to seek medical advice

- Temperature above 38°C
- if you have a central venous access device in place and it is itchy or red or appears infected.
- if you have chest pains
- if you have shortness of breath
- if you feel faint or dizzy
- if you feel like your heart is beating really fast

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

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

I still have questions?

If you still have any questions about thalassaemia, 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.

How to contact the SCAT centre

Sickle cell and thalassaemia centre

3rd Floor
Midland Metropolitan University Hospital (MMUH)
Smethwick
Birmingham
B66 2QT
Tel: 0121 507 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 search for us under Scatbham (this is a social site and shouldn't be used to seek medical advice)

Organisations that can help support you with your condition:

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

My Care Birmingham

www.mycareinbirmingham.co.uk

for support on Mental Health for minority groups. They have multiple links to services that may be useful.

United Kingdom Thalassaemia Society

<https://ukts.org/>

For more information about thalassaemia and the support available to you, visit the website <https://ukts.org> for the United Kingdom Thalassaemia Society.

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

For more information about our hospitals and services please see our website www.swbh.nhs.uk, like us on Facebook www.facebook.com/SWBHnhs or Instagram www.instagram.com/swbhnhhs.

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