

## Coventry and Warwickshire Children's Sickle Cell and Thalassaemia Services

### Service information

#### The service aim

Our service aim is to offer high quality care while considering our patients' physical, social, psychological and spiritual needs. We aim to promote our patients' health and. We can also signpost patients and parents who are planning a family. Your cultural and ethical beliefs and confidentiality are always respected. Our staff are supported with specialist training so that they are continually developing their skills.

#### Sickle cell disease and thalassaemia

Sickle cell disease and thalassaemia are the names we give to a group of related genetic conditions that affect the production of haemoglobin. Haemoglobin is the substance in our red blood cells that carries oxygen around the body.

These diseases may also be referred to as "Haemoglobinopathies".



## Patient Information

### **Our service users**

Most of our patients live in Coventry. However, UHCW also provides some specialist services for patients from across Warwickshire.

We are based at:

Children's Outpatients  
1st Floor Reception, West Wing  
University Hospital  
Clifford Bridge Road  
Coventry  
CV2 2DX

To find out how to get to the hospital, please visit:

<http://www.uhcw.nhs.uk/find-us/university-hospital>

Parking is available near the Women's and Children's entrance. Car parks can be found around the Accident and Emergency Department and the main hospital.

Drop off zones are outside the main entrance and the Women's and Children's Department. Public transport will drop off outside the main entrance.

### **Children's Haemoglobinopathy Team at UHCW NHS Trust**

Consultant Paediatrician Dr Farooqi & Dr Neuling

Secretary: 024 7696 7234

Specialist nurses: Amy Heap

Service hours: 9am – 5pm (Monday - Friday)

Secretary: 024 7696 7234

024 7696 4000 ask switchboard to Bleep 4566

024 7696 7248 Paediatric Specialist Nurses Office

Mobile: Amy- 0787 668 1069 Ring or Text

## Patient Information

### **Emergency Service and Out of Hours**

If you or your child has a sickle cell crisis or feeling unwell and you are unable to resolve the problem at home, go to the Children's Emergency Department and let the staff know that you have Sickle Cell Disease or Thalassaemia.

The staff in the emergency department will contact the on-call specialist doctor (haematologist). The specialist team will also be notified by our alert system. Please bring your personalised care plan (if you have one) to help us plan your treatment.

**Please bring any medication your child is taking and your child's red book to all appointments with a doctor or nurse.**

### **Our services:**

- Specialist consultant and nurses.
- Co-ordination of care for people affected by Sickle Cell & Thalassaemia.
- Clinics that provide specialist medical reviews for affected children on the 2<sup>nd</sup> and 4<sup>th</sup> Wednesday of the month between 9am - 12pm
- Joint children's clinic with a haematology specialist from Birmingham Children's Hospital every 3-6 months.
- Transcranial Doppler screening clinics to measure the blood flow in the brain.
- Link nurses on the wards.
- Training and education – for patients, parents, and health professionals
- Support parents and schools with developing care plans and education.
- Home visits.
- Phlebotomy service at UHCW to have blood taken for testing.
- Auditing and research. Including the support of the National Haemoglobinopathy Register.
- Links with the Children's Emergency Department
- Referrals and links with specialist services, including Endocrinology, heart specialists (Cardiology), Kidney specialists (Renal), Urology, Orthopaedic, and Maternity Specialists.
- Sign-posting to welfare and other social services

## Patient Information

The West Midlands Paediatric Haemoglobinopathy Network (WMPHN) was launched on 23 May 2016. The aim of the WMPHN is to bring about improved and standardised care for patients with cell disease and thalassaemia living within the West Midlands area. Find information about this at <https://www.westmidsstn.nhs.uk/>

## Other Departments

Children's Medical Day Unit, situated in the Children Unit, Ward 16.

This service is mainly available for blood transfusion.

Tel: 024 7696 7271

Open 9am – 6pm, Monday, Tuesday and Friday

Children's Wards:

Age 0 - 2 years old – Ward 15 contact number 024 7696 6595

Age 3 -12 years old – Ward 16 contact number 024 7696 7224

Age 13 -16 years old – Ward 14 contact number 024 7696 7432

Children's Outpatients Department:

Any queries or cancellations please contact 024 7696 7216.

## Other useful services

### Sickle Cell Society

54 Station Road  
London  
NW10 4UA

020 8961 7795

020 8961 8346

[info@sicklecellsociety.org](mailto:info@sicklecellsociety.org)

## Patient Information

### **UK Thalassaemia Society**

19 The Broadway  
Southgate Circus  
London  
N14 6PH

020 8882 0011

[www.ukts.org](http://www.ukts.org)

NHS Sickle & Thalassaemia Screening Programme

<https://www.gov.uk/topic/population-screening-programmes/newborn-blood-spot>

### **Help with Benefits**

024 7683 2000 or <http://www.coventry.gov.uk/benefits>

Customer Service Centre, Floor 1, Broadgate House, Coventry, CV1 2FS

### **Your views**

If you are unhappy about any aspect of care, please tell the Service Manager or another member of staff as soon as possible. They may be able to solve the problem straight away.

If you would prefer to speak to someone who is independent from the team delivering your care, you may contact our Patient Advice and Liaison Service (PALS). However, if you want to make a formal complaint, you need to write a letter or email the Trust's Complaints Manager.

PALS:

0800 028 4203 or [feedback@uhcw.nhs.uk](mailto:feedback@uhcw.nhs.uk)

ICAS for Coventry provided by HealthWatch Coventry:

024 7625 2011 or [ICAS@healthwatchcoventry.co.uk](mailto:ICAS@healthwatchcoventry.co.uk)

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Patient Advice & Liaison Service (PALS) University Hospital, Clifford Bridge Road, Coventry, CV2 2DX or email: [feedback@uhcw.nhs.uk](mailto:feedback@uhcw.nhs.uk)

The Trust has access to interpreting and translation services. If you need this information in another language or format, please contact us and we will do our best to meet your needs.

If you are a patient for appointments, please ring to book assistance – 024 7646 7234.

The Trust operates a smoke free policy.

### Did we get it right?

We would like you to tell us what you think about our services. This helps us make further improvements and recognise members of staff who provide a good service.

Have your say. Scan the QR code or visit:  
[www.uhcw.nhs.uk/feedback](http://www.uhcw.nhs.uk/feedback)



#### Document History

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