Moving to the Adult Haemoglobinopathy Service

Information for patients and their families
If you have thalassaemia, sickle cell anaemia or another sickling blood disorder in the Thames Valley, the Haemoglobinopathy Service will care for you. We are based at the Cancer and Haematology Centre at the Churchill Hospital, Oxford.

We offer long-term care for patients in Oxford and the surrounding areas, and work closely with district general hospitals. Although most of our patients have sickling disorders, we also look after patients with other inherited anaemias, including Hereditary Spherocytosis, Schwachman-Diamond syndrome and Diamond Blackfan anaemia.

Children under 16 (or 18 if in full-time education) are looked after by the Children’s Clinic in the Oxford Children’s Hospital, but when they are over this age they move on and come under the care of our service.

We understand that it can be difficult to move clinics and services, especially when you have been looked after by the same team for many years, so we plan to make it go as smoothly as possible for you. The process of moving from one service to another is referred to as ‘transition’. In the Children’s Clinic you will begin the transition process, with a series of helpful guides and information sessions. This is to prepare you for the move to the adult service, ensuring you have any information you need, a good understanding of your condition and its management. These sessions will also help prepare your parents/carers.

During the year that we expect you to move to the adult service, the adult nurse practitioner will join you in the Children’s Clinic and explain the final stages of the transition to the adult service. Following this appointment, your routine follow-up clinics will be at the Churchill Hospital. The first adult clinic appointment will be a joint meeting, with your children’s consultant, the adult nurse practitioner and your adult haematology consultant.

This ensures that your new team has all the information about your particular blood disorder, and is fully aware of your medical history and how your blood disorder affects you. It also means that you (and your parents / carers, if you wish) can discuss any questions or concerns you might have, in the presence of both your new and former doctors.
The Adult Haematology Service at the Churchill Hospital

There is an inpatient ward at the Churchill Hospital dedicated to patients with haematology disorders. There is also a Haematology Day Unit for procedures such as top-up blood transfusions. Exchange transfusions take place at the National Blood Service on the John Radcliffe site; we will introduce you to the Day Unit nurses if you are on a regular transfusion programme.

We offer haematological help and advice 24 hours a day, seven days a week. If you are worried about your anaemia (e.g. if you think you are having a sickle cell crisis, and need advice) you can call the Oxford Triage Assessment Team (during the day) or Clinical Haematology Ward (at night). The nurses will carry out a telephone assessment, and you will have the chance to speak with a haematology doctor, who may advise you to come to hospital for assessment or admission, if necessary.

Contact us

If you are unwell:
- Oxford Triage Assessment Team: 01865 572 192
  8.00am - 8.00pm seven days per week
- Clinical Haematology Ward: 01865 235 048/49
  8.00pm - 8.00am seven days per week

General contacts:
- Haematology Day Unit: 01865 235 554
  8.30am - 5.30pm Monday to Friday
- To change or make an outpatient appointment: 01865 227 826
  9.00am - 5.00pm Monday to Friday
- Haemoglobinopathies Service Coordinator: 01865 227 826
  Please use this number if you wish to contact Dr Atoyebi or Dr Hay
- Advanced Nurse Practitioner: 01865 227 826
Further information

We are always happy to discuss any questions you might have about exchange transfusion or any other aspect of your care.

We welcome your feedback; ask for a feedback form or email feedback@ouh.nhs.uk

For more information about the Churchill Hospital, please see: www.ouh.nhs.uk

Helpful websites

**NHS Choices**

**Sickle Cell Society**
http://sicklecellsociety.org

**UK Thalassaemia Society**
http://ukts.org

**Thalassaemia international**
www.thalassaemia.org.cy

**Brent Sickle Cell and Thalassaemia Centre, London North West Healthcare NHS Trust**
www.sickle-thal.nwlh.nhs.uk

If you have a specific requirement, need an interpreter, a document in Easy Read, another language, large print, Braille or audio version, please call 01865 221 473 or email PALSJR@ouh.nhs.uk

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