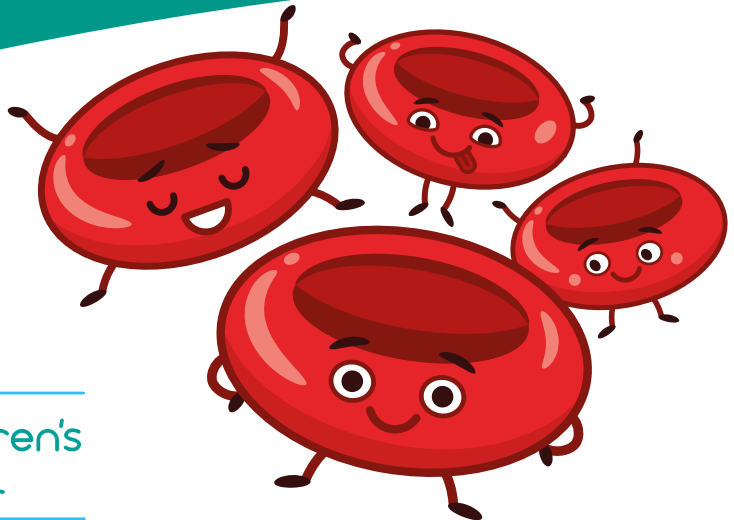


Telephone clinic: for children and young people with sickle cell disease who are taking hydroxycarbamide

Information for parents
and young people



Leeds children's
hospital

caring about children

Why have I been given this leaflet?

Your child's haematology team are aware that coming to the hospital for appointments can mean waiting around for a long time. There are also some occasions where seeing a doctor is not necessary for your child.

Because of this, the children's haematology team have developed a new, more efficient and safe way of prescribing hydroxycarbamide, and looking after children who are taking it. You have been given this leaflet because your child is able to receive some of their sickle cell care in this new way.

What would change?

Instead of every appointment being in the hospital with a doctor, some of your child's appointments will be over the telephone with the haematology nurse specialist. The nurse specialist will review your child by asking you a series of questions about their health, sickle cell disease and how well they are managing to take medicines.

During this appointment, your child's dose of hydroxycarbamide will be reviewed by a nurse and pharmacist. Any changes to your child's usual dose will be shared with you and you will be told what to do next.

How will I collect the hydroxycarbamide?

The medicines will be sent to a Boots pharmacy nearest to your house, you will need to collect them from there. The haematology nurse and pharmacist will let you know when to collect the medicine.

Will my child still need to have blood tests?

YES. Blood tests are very important in helping your child's haematology team to assess their health, as well as making sure that the dose of hydroxycarbamide is safe and is helping your child as it should.

Your child will have their blood tested at the same time points for as long as they are taking hydroxycarbamide. These are:

1. 2 weeks after starting hydroxycarbamide.
2. 2 weeks after any change in dose.
3. Every 8 weeks, as long as there are no unwanted symptoms of sickle cell disease and the previous blood tests have been normal.

Your haematology nurses will tell you when and where your child should have their blood taken.

What else do I need to do?

In order for these appointments to work for you and your child, there are a few things you will be asked to do:

1. Make sure you are available to talk on the phone at the appointment time that has been sent to you.
2. Make sure your child has their blood tests at the time you agreed with the haematology nurse.
3. Make sure you collect the hydroxycarbamide before you run out at home.
4. Make sure you return any leftover medication to the hospital each time you come to see the doctor.

If my child is well, do they ever need to see a doctor?

YES. It is very important that your child does still see a haematology doctor. The frequency with which this will happen depends on the following:

1. how well they are;
2. whether they have having problems with their sickle cell disease; and
3. whether they are having problems with taking medication.

If your child is very well and not experiencing any problems with their sickle cell disease, they may only need to come to hospital to see a doctor twice per year. This is the same frequency with which your child would be seen if they were not taking hydroxycarbamide.

Your child's haematology team will guide you through the appointment types needed.

What if I or the haematology nurse thinks my child needs to see a doctor?

If you are worried that your child needs to see a haematology doctor, you should not wait until your telephone appointment with the nurse. You should call the haematology nurse specialist, the outpatient department or the ward straight away for advice. All contact numbers are on the back of this leaflet.

If, during the telephone appointment, the haematology nurse feels your child should see a doctor, you will be told the reason. An appointment will then be made with a doctor, or arrangements made for your child to visit the ward for assessment.

Does my child have to receive their care this way?

NO. The most important thing to understand is that you can choose whether or not you want to make use of this new service. If you would like to try it but find it does not work for you, it is also fine to go back to your usual hospital visits.

What happens if I cannot make an appointment?

You will receive an appointment letter and a reminder text message for your child's hospital or telephone appointments.

If you know you cannot make the appointment that has been given to you, it is important that you call the number on the letter to cancel. A new appointment will then be arranged for your child at a time that suits you.

What happens if I miss appointments?

You should always let the hospital know if you cannot make an appointment. If you are not available to speak to the haematology nurse at the time you have been sent, this will be recorded as "did not attend" (DNA) on your child's record. A total of three DNAs will result in this service being withdrawn from your child. If this should happen, all of your child's appointments would go back to being with a doctor in the hospital.

Contact details

If you have any questions or concerns, please contact:

Haematology Clinical Nurse Specialist: Suzie Preston

Tel: **(0113) 3926867** Mobile: **07775 228860**

Haematology Clinical Nurse Specialist: Ben Sykes

Mobile: **07787 266096**

Ward L31 (0 - 13 years): **(0113) 3927131**

Ward L31 (13 - 18 years): **(0113) 3927133**



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