

Queensland Paediatric Haematology Service

Sickle Cell Disease

When and who to contact

General Practitioner or Medical Centre

It is very important that your child has a regular general practitioner (GP) as this is your link to a health care provider in the community. Your GP can help you and your child with common childhood illnesses, regular vaccinations, non blood disorder related health conditions and health care referrals to specialists.

Sick Day Action Plan

It is very important that your child has a regular GP as sometimes children with blood disorders will have common child related illnesses or conditions, such as cold or flu like symptoms, ear infections, skin conditions. If you are experiencing any of these symptoms you should visit your GP or nearest medical centre to have your child reviewed. If your GP has further concerns he/she can contact your health care team.

Medical Emergency Action Plan

You will have been given specific information related to your child's blood disorder and the warning signs of a more serious condition. If you suspect any of these symptoms you should take immediate action. Please contact the Haematology team for advice or present to your nearest hospital emergency department. If your child is very unwell call for an ambulance on **000**.

Symptoms

Some of the symptoms that are considered serious include:

- Your child is having a painful episode, which is not controlled with paracetamol (Panadol) and Ibuprofen (Neurofen).
- Cannot move one side of their body or one or two of their limbs.
- If you notice your child is much more pale and lethargic than usual.
- Difficulty breathing.
- If your child has a temperature above 38 degrees and is very lethargic, has rigors (shivers and shakes). If your child has a fever but is otherwise well, you may be able to see your local doctor (GP) initially if it is possible to see them on the same day.
- If you feel your child is severely unwell.

REMEMBER: Your child will be seen by a doctor in the Children's Emergency department. The Emergency team will contact the haematology consultant on call to discuss your child's condition.

Enquiries

Non-urgent

Please email LCCH-Haemophilia@health.qld.gov.au if you need assistance with stock and supply orders, travel letters for your medication, school health action plans, or information on port or vein training. Please allow five working days for us to action these requests.

Clinic appointments

Please call the Outpatient Bookings Office on **1300 762 831** or email LCCH-Outpatients@health.qld.gov.au. Your health care team does not make these bookings or any changes to your appointments.

Outreach or telehealth appointments

Please email any queries about these clinics to LCCH-Haemophilia@health.qld.gov.au.

Blood results

- **Urgent** - Your health care team will contact you if required.
- **Routine test /under investigation / follow up tests** - Please ensure you have a follow-up appointment booked. Blood results will not be discussed over the phone.

Scripts

Ideally scripts should be requested at your regular review appointment. If your child has a repeat prescription please check with the Queensland Children's Hospital Pharmacy how many repeats you have left and if you need a new script.

- Pharmacy (Level 2e) open from Monday to Sunday 9am - 5pm. Tel: **07 3068 1934**.
- For Repeat Prescriptions call **07 3068 1993** (press 1 and leave a message) or email LCCHPrescriptionRepeat@health.qld.gov.au.
- If a script can be done by your GP, your health care team will direct you to do so.

Referrals

It is important that you ensure you have a valid referral from your GP for all appointments. Sometimes an indefinite (ongoing) referral may be appropriate if you are coming to clinic many times a year, please discuss this with your GP. Your GP can send your referral to the Referrals Centre Fax Number 1300 407 281.

Useful patient and family resources

- Children's Health Queensland website - www.childrens.health.qld.gov.au/qch/
- Clinical Equipment and Consumables
Central Resource Service (CRS) - **07 3068 4720** or CHQ_CRS@health.qld.gov.au
- Interpreter Services - Please ask staff for assistance

For medical issues related to your child's sickle cell disease

Monday – Friday (8am - 4pm)	After hours, weekends and public holidays
Nurse phone - 0457 719 233	Contact the Queensland Children's Hospital switch on 07 3068 1111 and ask for the Haematology Consultant on-call.
Doctor (Registrar) - 07 3068 4562	