

Sickle Cell Pain Episodes

Information for patients and families

Read this information to learn:

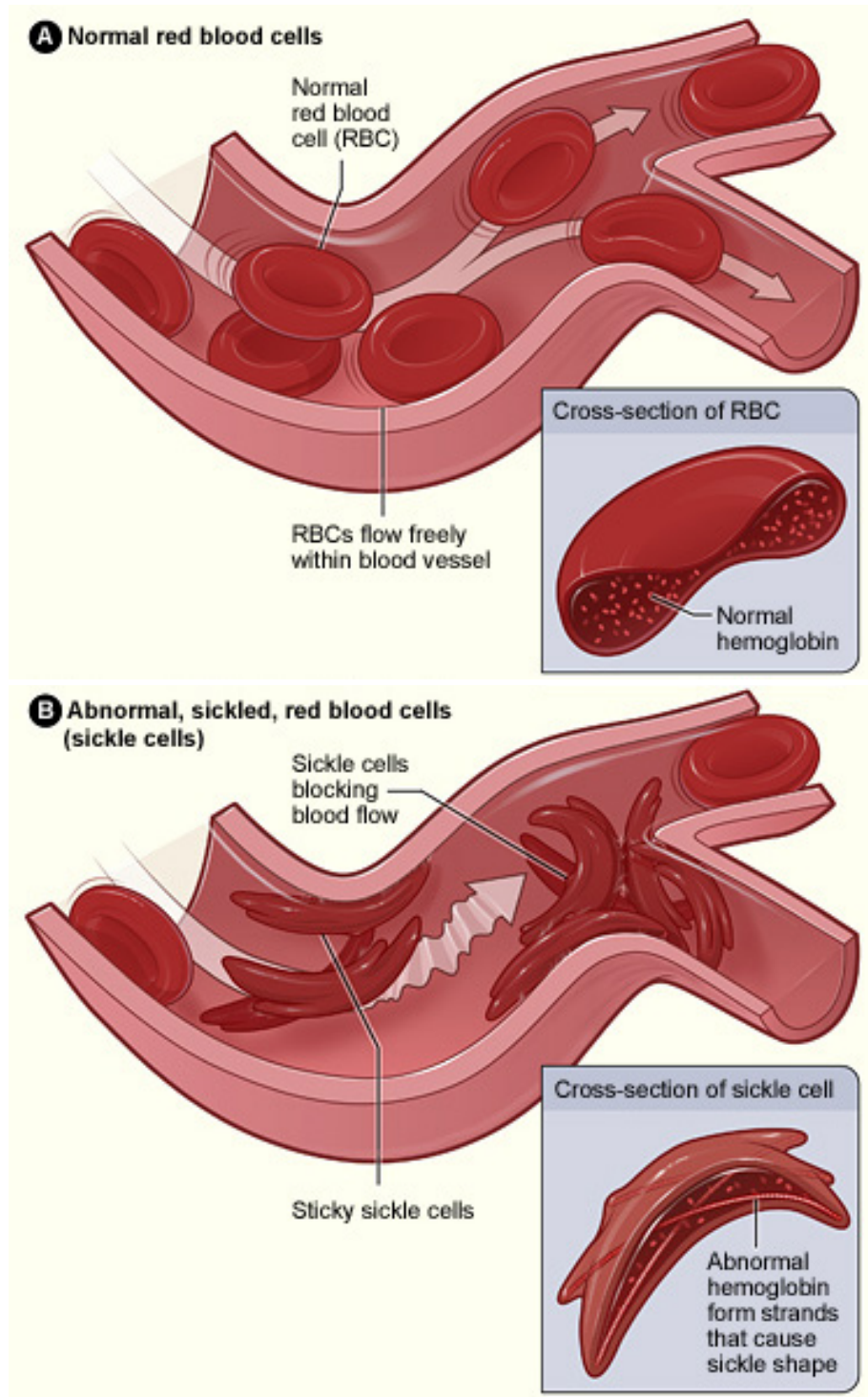
- what a sickle cell pain episode is
- what can cause it
- what to do if you have a pain episode
- how it is treated



What is a sickle cell pain episode?

A sickle cell pain episode happens when the tissues of your body do not get a normal amount of blood flowing to them.

During a sickle cell pain episode, more and more red blood cells start to turn into a sickle shape and become very sticky. They can no longer pass through your blood vessels easily. This can block the flow of blood and cause severe pain.



How will I know if I am having a sickle cell pain episode?

You may feel pain in your:

- arms
- hips
- legs
- chest
- back

What can cause one to start?

There are many things that can cause a pain episode to start.

It may start if you:

- are dehydrated (do not have enough water in your body)
- have an infection
- were out in very cold or hot weather
- smoke, use drugs, or drink too much alcohol
- are pregnant
- are on your period
- feel a lot of stress or are unable to sleep (or both)
- are recovering from surgery

What should I do?

1. Take your usual pain medicines such as acetaminophen (Tylenol) or ibuprofen (Advil) and opiates such as Tylenol 3, morphine or hydromorphone (Dilaudid). Follow the instructions your doctor or nurse practitioner gave you for taking them.
2. Drink lots of fluids.
3. Get some rest.
4. Keep warm by using warm blankets and heating pads if you are cold.
5. Call the Red Blood Cell Disorders Clinic at 416 340 4882 and press 3 to leave a message for the nurse practitioners if you need pain medicine or advice for treating your pain.
6. Keep taking your hydroxyurea (Hydrea). Follow the instructions your doctor or nurse practitioner gave you for taking them.



Go to the nearest emergency department if you have:

- very bad pain in your abdomen or chest
- difficulty breathing
- pain that does not go away or gets worse after you have followed Steps 1 to 6 in “What should I do?”
- a fever higher than 38 °C or 100.4 °F
- vomiting or diarrhea or both
- a painful erection that will not go away
- pain that does not seem like your usual sickle cell pain

What to bring with you:

- ✓ All the medicines you take
- ✓ This document
- ✓ Your Red Blood Cell Disorder (RBCD) Clinic contact card. Show it to the doctor so they can talk to the RBCD team about your care.



If you do not have the RBCD Clinic Contact Card, please ask for one at your next appointment.

When you arrive at the emergency department

Provide this information

- the history of your sickle cell disease
- which pain medicines you have already taken and when you last took them
- which pain medicines usually help you when you have a sickle cell pain episode

Important:

- Ask for the standard treatment protocol for sickle cell pain episodes
- Blood transfusions are not usually required for sickle cell pain episodes

What treatment may I get for my pain episode?

The emergency department team may give you:

- pain medicine to help control your pain.
- an intravenous (IV) line in your vein if you are not able to drink
- oxygen to help you breathe

What if I am admitted to the hospital?

If you are admitted to Toronto General, Toronto Western or Mount Sinai Hospital, a member of the RBCD team will come to see you.

If you are admitted to another hospital, please ask the doctor or nurse to contact the RBCD team. Show them your contact card or this information. We are always available to give advice by phone or email to other health care providers.

- Ask to see a social worker for more support.
- Call the RBCD Clinic to schedule a follow-up appointment after you leave the hospital.
- If you feel you do not have enough pain medicines until we see you in clinic, please let the RBCD Clinic know.
- Ask the hospital staff to send a copy of your discharge summary to the RBCD Clinic.

Who can I contact?

The Red Blood Cell Disorders Clinic

7th Floor – Norman Urquhart (NU) Building
Toronto General Hospital, UHN
200 Elizabeth Street, Toronto, ON M5G 2C4
Phone: 416 340 4882 | Fax: 416 340 4559

Your RBCD Clinical Team

Dr. Richard Ward – Medical Director
Dr. Kevin Kuo – Hematologist
Dr. Jacob Pendergrast – Hematologist
Sinthu Srikanthan – Social Worker
Colleen Johnson – Nurse Practitioner
Hasumie Hosogoe – Nurse Practitioner
Omar Florez – Administrative Assistant
Vanessa Loiacono – Manager

Patient Relations

Please speak to your health care team for questions or concerns.
Call the Patient Relations team if you need more help.

To speak with a Patient Relations team member:

Phone: 416 340 4807

Email: patientrelations@uhn.ca



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