START HERE

Your First Steps Guide

A plain-language introduction to sickle cell disease and what to expect in the days and weeks after diagnosis — for you, or for someone you love.

Need to talk to someone right now?
If you are in crisis or need immediate support, please reach out to a professional.
Talk Suicide Canada: 1-833-456-4566 | **Sickle Cell Canada Support:** sicklecellanemia.ca/support | **Emergency:** call 911 or go to your nearest emergency room.

What is sickle cell disease?

Sickle cell disease (SCD) is an inherited blood disorder. Red blood cells, which are usually round and flexible, form a rigid, crescent ("sickle") shape. These misshapen cells can block blood flow and break down faster than the body can replace them, which is why anemia and pain episodes are common features of the condition.

SCD is caused by an inherited change in the gene that makes hemoglobin, the protein in red blood cells that carries oxygen. A person develops SCD when they inherit the sickle gene from both parents. It is present from birth, though it's sometimes not diagnosed until later in childhood or adulthood.

You are not alone

It's completely normal to feel shock, grief, fear, or even relief at finally having an answer — sometimes all in the same week. Thousands of people across the BHASNet community have walked this path before you, and many are ready to share what they've learned. There is no "right" way to feel right now.

Your first two weeks: a rough roadmap

- **Get connected to a hematologist.** Ask your family doctor or the diagnosing hospital for a referral to a hematology clinic that treats sickle cell disease, ideally one with experience in SCD specifically.
- **Start a simple health file.** A folder (paper or digital) for test results, medication lists, and appointment notes will save you time and stress later.
- **Learn your genotype.** Ask your care team which form of SCD you or your child has (for example HbSS, HbSC, or HbS beta-thalassemia) — this affects what to expect and how it's managed.
- **Ask about hydroxyurea and vaccinations.** Many people with SCD benefit from disease-modifying medication and additional vaccines; your hematologist can advise on what's right for you.
- **Identify your nearest emergency department** and let them know about the diagnosis in advance if possible, especially if pain crises have already occurred.

- **Find your community.** Peer support — people who have lived this — is one of the most consistently helpful resources people describe. See the Peer Support section of the BHASNet website when you're ready.

Recognizing a pain crisis (vaso-occlusive episode)

A pain crisis happens when sickled cells block blood flow, most often in the back, chest, arms, legs, or abdomen. Pain can range from mild to severe and may come on suddenly. Triggers can include dehydration, cold weather, infection, high altitude, and stress — though sometimes there's no clear trigger at all.

- Mild episodes are often manageable at home with fluids, warmth, rest, and over-the-counter pain relief as advised by your care team.
- Seek urgent medical care for: fever over 38.5°C (101.3°F), chest pain or difficulty breathing, severe unrelieved pain, sudden weakness or vision changes, or a pain episode that feels different from previous ones.

Everyday habits that help

- **Stay well-hydrated** throughout the day, more than you might think you need.
- **Avoid extreme cold** and dress warmly in cool weather.
- **Avoid high altitudes and low-oxygen environments** without medical guidance (this includes some flights and mountain travel).
- **Treat infections early** and stay up to date on recommended vaccinations.
- **Pace physical activity** and rest when your body signals you to.
- **Keep every hematology appointment**, even when you're feeling well — routine monitoring catches problems early.

For parents and caregivers

If your child has just been diagnosed, ask the care team specifically about newborn screening follow-up, penicillin prophylaxis (common in early childhood), school communication plans, and what symptoms should prompt an immediate call to their care team. You are allowed to ask the same question twice, or a hundred times, until it makes sense.

What to bring to BHASNet

When you're ready, the BHASNet Library has plain-language guides and more clinical material side by side, Peer Support connects you with people who've been through it, and our news and stories pages follow research and community milestones. Start wherever feels manageable today — there's no timeline you need to keep to.

A note on this guide: This document offers general, plain-language information and is not a substitute for personalized medical advice. Always follow the guidance of your own hematology team for diagnosis, treatment, and emergency care.