

WORLD SICKLE CELL DAY 2024



We Are
Stronger Together
Building a Future for Sickle Cell Care

What can we do as a community?

For World Sickle Cell Day, we're asking people to:

- **Donate blood.** More ethnically matched blood is needed from the black heritage community for blood transfusions for people with sickle cell, and with hospitals needing 250 donations a day for sickle cell, it's important that we all encourage people to donate.
- **Get Tested.** If you are planning a family, or already pregnant, you and your partner can ask your GP for a test. It will give you information about the likelihood of your future children inheriting the condition.
- **Talk about sickle cell.** Download some of our information booklets and share them with your employer, school, college or university, friends and family. Check out our FAQs under 'social welfare' which covers a range of topics from general information leaflets about sickle cell, to housing, benefits, nutrition, employee support and much more
- Get together with your friends and family and take part in **volunteering** or **fundraising activities** with us. From social media fundraisers to collections, fun runs, marathons and special events, there's lots of ways to support us.....
-or simply make a **donation**
- **Become an Ambassador** – We have an incredible community and are always looking for individuals with sickle cell to share their experiences. By doing so, you can help others better understand sickle cell disorder. If you have a story to share or simply want to help, our communications team would love to hear from you.
- **Follow us** on social media to get the latest news and updates
- Sign up to receive our newsletters. see '**become a member**' on the homepage of our website
- Get involved in **medical trials** and **research studies**. This will help to make progress in the understanding of sickle cell disorder, and the development of new treatments.
- Attend our **meetings** and **events**. Offer your feedback, and hear from clinical experts

Scan here to donate



#worldsicklecellday

If you have sickle cell, we're here to help:

- Use our email and telephone [advice line](#)
- Join your local sickle cell [patient group](#)
- If you or someone in your family are aged 10-24, registered with a GP and receiving sickle cell care in London, refer them/yourself to our [children and young people's mentoring programme](#) for one to one support with sickle cell. Our mentors can help with understanding and managing the condition, transitioning from child to adult hospital services and getting involved in the local community. See our website and socials for more details.
- Buy a [prescription prepayment card](#) (England) to help save money on your prescriptions
- Ask your healthcare provider about your [sickle cell patient card](#) to show to ambulance staff and/or A&E if you access hospital care in England during a crisis. The card helps to explain that you are a sickle cell patient and have a right to pain relief within 30 minutes of arrival.

The NHS is committed to improving sickle cell care, and they are introducing new systems and trialling new approaches in some locations. Ask your healthcare team if these NHS services are available in your area yet :

[Digital Care Plans](#) – where you will be able to access your own medical records online. This might be of particular benefit if you are away from home, and need care at a hospital you have never visited before.

[Hyper Acute Units](#) – new specialist NHS centres where sickle cell patients can receive specialist support, meaning you can avoid waiting in A&E, and instead go straight to clinicians who understand the condition and can provide effective pain relief faster.

[Sickle Cell acronym](#) in A&E units – this is a short term pilot study in some (not all) A&E units in 2024. The project is measuring how useful it is to use an acronym : 'ACT NOW' for A&E staff to quickly access information about the steps they should go through if someone arrives and says they have sickle cell and are experiencing a crisis. For example, the 'A' in ACT NOW stands for 'analgesia', and gives the clinician the guideline that they should be administering pain relief to you within 30 minutes of your arrival.

A= analgesia

C= compassion

T= test (blood tests)

N= notify (ie specialist haematology team)

O= oxygen (supply it if required)

W= watch (make regular observations)



NHS

If you live with Sickle Cell, you could save money on your prescriptions

Find out if you can get free prescriptions by using the eligibility checker at www.nhsbsa.nhs.uk/check.

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