# Sickle Cell Society

## World Sickle Cell Day 19 June 2025 : theme briefing

We are proud to unveil our theme for World Sickle Cell Day 2025:

**Tell it Loud.**

It’s a bold, energising call to action for everyone to raise their voice for sickle cell. Whether through personal stories, art, creativity, advocacy, media or community initiatives, we’re asking people to not only mention sickle cell disorder, but shout about it in whatever way has meaning to them. We aim to bring attention, inspire change, and create momentum.

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## Why “Tell it Loud”?

Sickle cell disorder is the UK's fastest-growing genetic disorder. It affects around 17,500 people, and the demand for blood donations to treat patients with sickle cell has increased significantly.

People living with sickle cell, their families, and healthcare professionals know that the condition is too often overlooked or misunderstood, leading to shame, fear, stigma and poor healthcare experiences. “Tell it Loud” flips the script. It’s about pride, strength, visibility and community. It invites everyone — from grassroots advocates to global partners — to speak up, be heard, raise awareness, educate, and amplify what matters.

Storytelling is a powerful tool that can create change and reduce stigma. Tell it Loud calls on people to speak their truth and tell their stories - but it’s about more than being vocal. We know that in the sickle cell community there are very talented creatives who use their skills to raise awareness for sickle cell. So, whether you’re writing poems or rhymes, painting, drawing or etching, filming social content, or writing a script for Netflix – everyone can ‘Tell it Loud’ in their own way.

## How Does *Telling It Loud* Create Change?

We’ve already seen the power of raising our collective voices.

In 2024, the release of Supacell on Netflix sparked a global conversation about sickle cell disorder. Google Trends showed a dramatic spike in searches and discussion, proving that mainstream representation can educate, shift perspectives, and spark curiosity about conditions that are often overlooked. Open dialogue around Supacell helped shine a light on sickle cell and sickle cell trait — reaching new audiences and building understanding in communities that may never have heard about it before.

That same year, we worked closely with the sickle cell community to elevate personal stories about why access to gene therapy matters. Hundreds of people came forward to *tell it loud* — sharing powerful testimonies, hope, and urgency with policy makers and regulators. That collective voice helped drive change: Exa-cel (Casgevy) was approved for NHS use in England, becoming the first gene therapy available for people with sickle cell in the UK.

This is the impact of speaking out. When we tell it loud — and do it together — we change minds, shift policy, and create a future with better care, more options, and greater understanding.

## Why Now?

We’re calling on everyone to *Tell it Loud* in 2025 because sickle cell care in the UK is at a turning point.

The NHS is undergoing major changes, and there are real concerns that services for sickle cell patients could be weakened or lost in the shuffle. Integrated Care Boards (ICBs) — the local NHS bodies now responsible for commissioning sickle cell services — have been told to cut their running costs by **50%**. That puts pressure on the very systems that support specialist care: commissioning, planning, improvement programmes, and transition services for young people moving into adult care.

We already know that the quality of care for sickle cell patients isn’t consistent. Some hospitals do a great job — others are struggling. Young people in particular are at risk of falling through the cracks during the critical transition period. And now, with NHS reorganisation and budget cuts looming, the risk is that care could be affected.

At the same time, wider government policies — such as potential cuts to disability-related benefits — risk making life even harder for people living with long-term conditions like sickle cell. Support in the workplace is also still lacking. Too many people with sickle cell are misunderstood or unsupported by their employers, facing barriers to flexible working, time off for treatment, or reasonable adjustments. That’s why we’re calling for action to improve workplace rights and awareness — so that people with sickle cell are not only seen, but properly supported.

That’s why we need to *Tell it Loud*.

We must remind policymakers, NHS leaders and the public that sickle cell care **must improve**, not decline. That investment, planning and expertise are essential. That the sickle cell community will not be ignored. And that progress — like the recent approval of gene therapy on the NHS — must be matched with better everyday care for everyone living with this condition.

## ACTION!

To tell it loud on World Sickle Cell Day this June, you can do two things :

1. Share your stories, creativity, and more. Use the hashtags and create some noise. Below there are ideas about what you can do.

2. Write to your MP using the template letter linked below, to ask them to support a motion currently in Parliament for better workplace protections for people living with sickle cell disorder.

## How do we tell it loud to our MP?

This year, one powerful way to *Tell it Loud* is to support a new **Early Day Motion (https://edm.parliament.uk/early-day-motion/63308 )** in Parliament, calling for better workplace rights for people living with sickle cell.

Too often, people with sickle cell face misunderstanding, discrimination, and inflexibility at work — from being denied medical leave to struggling to get reasonable adjustments. Despite being a serious lifelong condition, sickle cell is still not consistently recognised or supported by employers.

This motion urges the UK Government to:

- Recognise sickle cell as a workplace disability under the Equality Act
- Deliver awareness training for employers, HR teams and occupational health

- Expand **Access to Work** support, including help with travel and flexible working

**We need this to happen, and so do thousands of people of working age, that live with sickle cell.**

**Help us Tell it Loud in Parliament :**

1. Look up your MP and their contact details here https://www.parliament.uk/get-involved/contact-an-mp-or-lord/contact-your-mp/

2. Have a quick look at the early day motion web page to see if your MP has already signed : https://edm.parliament.uk/early-day-motion/63308

3. **If they haven't - ask your MP to sign the early day motion using this downloadable letter template. Simply save a copy (click 'share and export') and you can add your name and any other information you'd like before sending it : https://docs.google.com/document/d/1FJf-Too38cJp0OSQKYi8So0o5SzcXWuU/edit?usp=drive_link&ouid=106899888616348982102&rtpof=true&sd=true**

4. Share the link to the early day motion far and wide so it gets more visibility and ask friends and family to write to their MP

The more MPs that back this motion, the louder our message will be — and the closer we'll get to change that matters.

## More ways to Tell it Loud on June 19th

### Wear Red for Sickle Cell!

It's a World Sickle Cell Day tradition — and this year, it's the perfect way to *Tell it Loud*. Red is bold, powerful, and impossible to ignore. Wear red to show your support and help support the Tell it Loud message. Share your red outfit selfies on social media and use the campaign tags so we'll see you!

### Sickle Cell Patients and Families

Your voice matters most. Share your journey, your creativity, or what you wish people understood about life with sickle cell. From TikToks to testimonials, art to advocacy — this is your platform to #TellItLoud and to be #LoudEnough

### Sickle Cell Community Groups

Use #TellItLoud and #LoudEnough to showcase your local activities, share lived experience stories, and highlight the voices in your community. Whether it's a storytelling event, social media campaign or community mural, we want to help amplify your work.

### Influencers and Creators

Your platforms can drive real change. Whether you're a health advocate, lifestyle creator or community voice, lend your reach to this cause. Post, share, or partner with us — and help Tell it Loud.

### Creatives

Whether you're a poet, painter, designer, dancer, musician, filmmaker or photographer — your art has the power to move people and spark change. Share your creations inspired by sickle cell — whether they reflect lived experience, raise awareness, or celebrate resilience. Perform them, post them, and use your platform to *Tell it Loud*. Don't forget to use the campaign hashtags so we can see your work — we'd love to spotlight and reshare as many creative contributions as possible.

### Blood Donation Advocates

Blood donors are lifesavers. Use #TellItLoud to promote black and brown heritage community donation and donor stories, and to raise awareness of the ongoing need for ethnically matched blood for transfusions. Collaborate with our **Give Blood, Spread Love**, **England** team to amplify the message.

### Media and Journalists

We're making noise — and we need the media to help amplify it. Let us know about lived experiences so we can approach journalists to Tell it Loud.

### Hospital Teams

You play a vital role in changing perceptions and improving understanding of sickle cell. Use your expert platform to educate, challenge myths, and raise awareness about the treatments and care you provide. Share real stories of innovation, progress, and the compassion at the heart of your work. Highlight how your team is putting the **ACT NOW** acronym into action to improve outcomes. Encourage both staff and patients to get involved — whether through sharing stories, participating in events, or posting on social media. This is your chance to *Tell it Loud* and show the impact of excellent care in action.

Pharmaceutical Companies

We love to see work being done to develop new safe and effective treatments for sickle cell. Join the movement by spotlighting how your work supports the sickle cell community. Share your commitment to access and equity, and to improving the treatment landscape for sickle cell. Use your platforms to amplify patient voices and spread awareness far and wide.

## Join Us

We'll be providing online materials on our website to make it easy for everyone to take part. Whether it's a tweet, a video, a podcast, or an event — we want you to Tell it Loud for sickle cell.

## Campaign hashtags :

**#TellItLoud** is the primary and most important hashtag to use for the campaign. Use #LoudEnough as a second hashtag to reinforce the message, and don't forget to tie it all together with #WorldSickleCellDay2025

## For partnerships, resources or more information

Contact us at communications@sicklecellsociety.org