

Sickle cell and stem cell transplant

A Guide



If you've been told that a stem cell transplant is now a treatment option for your sickle cell disorder, you probably have a lot of questions as there's a lot to think about.

Hopefully this leaflet will help. Take it home with you and read it with your family and friends. You can also find more information at anthohnolan.org/sicklecell

Remember

Your healthcare team will know your unique medical situation best. But this information will help guide you through what can be a tricky process.

Can I have a stem cell transplant if I have sickle cell disorder?

Yes, having a stem cell transplant to potentially cure your sickle cell disorder has been an option on the NHS for adults in the UK since 2020.

You can understand more about the stem cell transplant process at anthohnolan.org/understanding

You will only be offered a stem cell transplant if the benefits outweigh the risks. In this case, you may have severe sickle cell disorder which:

- cannot be controlled with pain management or other treatments
- means you spend a lot of time in hospital to treat your acute pain episodes
- affects your quality of life so you cannot go to work, take part in education, socialise, or carry out normal day-to-day activities
- causes or puts you at high risk of complications such as a stroke, organ dysfunction (where your organs do not work properly), acute chest syndrome (a lung condition causing chest pain and breathing difficulties), and infections
- puts your life at risk.

Important

You can only have a stem cell transplant if you have a matched related donor. This is a family member who is a match and can donate their stem cells to you.



“Living with sickle cell meant constantly putting my life on hold. I lost jobs and missed out on opportunities because of the unpredictable crises. Choosing to have a stem cell transplant gave me the chance to take control of my future. Now I’m not just surviving, I’m thriving – and building the life I’ve always wanted.”

RONKE WHO HAD A SUCCESSFUL STEM CELL TRANSPLANT TO CURE HER SICKLE CELL DISORDER

ANTHONY NOLAN

What are the risks and benefits?

A stem cell transplant can cure sickle cell disorder, which is simply fantastic. But a transplant is an intensive treatment which comes with a lot of risks and benefits to consider.

Benefits

- A stem cell transplant can **cure** your sickle cell disorder.
- You can expect your **pain episodes to stop**, but this may take some time. You might experience chronic pain because of your sickle cell disorder. Your pain management will be controlled carefully after transplant if this applies to you. This will all depend on your individual situation.
- A stem cell transplant should **prevent further complications** caused by your sickle cell disorder, like problems with your eyes and organ dysfunction. Any sickle cell related problems with organ function that you already have will probably not get any worse.
- You can have a **better quality of life**. You may be offered a transplant if your severe sickle cell disorder affects your day-to-day life and you do not respond well to any other treatments.

Risks

- Any **current complications you have from your sickle cell disorder**, like liver failure or heart conditions, could put you at risk during a stem cell transplant. Your medical team can talk you through how well your body could cope with a transplant.
- **Graft versus host disease (GvHD)** is a potentially life-threatening side effect of a stem cell transplant. This is where your new stem cells start to attack other cells in your body. You can read more about GvHD at anthonymolan.org/gvhd

GvHD is not always life-threatening and the risk of GvHD is much lower for people with sickle cell disorder. But it is a big risk to consider.
- You will need to have conditioning therapy before your transplant. Conditioning therapy prepares your body to receive your new stem cells and you're more at risk of infection during this time.

Sickle cell patients receive a less intense form of conditioning therapy. This lessens the risk of complications. Currently, for people with sickle cell disorder, conditioning therapy is made up of an immunosuppressive drug and low dose radiotherapy.

You can read more about conditioning therapy at anthonymolan.org/conditioning

Important

A stem cell transplant will not necessarily improve any complications caused by your sickle cell disorder. You may still need treatment for these complications after transplant.



“I was quite scared to go ahead with a transplant but at the same time I felt like it was the only option if I wanted to have a better quality of life.”

IGGIE WHO HAD A SUCCESSFUL STEM CELL TRANSPLANT TO CURE HER SICKLE CELL DISORDER

FAQs

I thought only cancer patients had a stem cell transplant. Is it that serious?

Even though people with cancer do have stem cell transplants, it does not mean that you also have cancer or are on the same journey. Parts of the treatment that you may associate with cancer, like chemotherapy and radiotherapy, are different for sickle cell disorder patients.



Will having a stem cell transplant affect my fertility?

Conditioning therapy before transplant can make it more difficult to get pregnant without some professional support, like IVF. Your risk of fertility issues will be lower if your conditioning therapy does not include chemotherapy. Your medical team will talk about your risk of fertility issues with you. For further information see anthonymolan.org/fertility

Important

Even though having a stem cell transplant can cure your sickle cell disorder, you will still carry the sickle cell gene. This means that you can still pass it on to your children, even after your transplant.

How much time will I need to take off work?

You'll likely need to take at least six months to a year off work. Exactly how much time you need to take off work, or from education, will depend on your individual situation and recovery.

Can I get any financial support?

Yes, there is support available to help ease any money worries you may have. It's common to feel anxious about your financial situation. But we're here to help in any way we can. You can find more support at anthohnolan.org/managingfinances

You might be eligible for an Anthony Nolan Grant: anthohnolan.org/grant

You can read more FAQs about sickle cell and stem cell transplant at anthohnolan.org/sicklecell



Where can I find further information and support?

The Anthony Nolan Patient Services team is here for you. We can answer questions, support you with any worries you have, and connect you to any practical help you need.

You can call our helpline on **0303 303 0303** or email patientinfo@anthohnolan.org. Our opening hours are 9am to 5pm, Monday to Friday.

- The **Sickle Cell Society** supports and represents people with sickle cell disorder. You can find lots of information and advice on their website: sicklecellsociety.org
- The NHS also has information about sickle cell disorder, including symptoms, treatments, and living with sickle cell disorder, on their website: nhs.uk/conditions/sickle-cell-disease
- To find out about other treatments for sickle cell disorder – including gene therapy and Red Cell Exchange – please speak to your medical team. We have further information at anthohnolan.org/sicklecell

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If you have any questions or comments about this resource, or would like information on the evidence used to produce it, please email: patientinfo@anthonymolan.org

The information contained in this booklet is correct at the time of going to print (Sept 2025). We plan to review this publication within three years. For updates or the latest information, visit anthonymolan.org



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