

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 disease patients.

Will having a stem cell transplant affect my fertility?

Conditioning therapy before transplant can cause difficulty in conceiving without some professional support, like IVF. If your conditioning therapy doesn't include chemotherapy, you will be at lower risk of fertility issues. Your medical team will talk about your risk of fertility issues with you.

Important: Even though having a stem cell transplant can cure your sickle cell disease, 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 entirely depend on your individual situation and how you are recovering.



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 disease in 2019



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 anthonymolan.org/managingfinances

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

You can read more FAQs about sickle cell and stem cell transplant at anthonymolan.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 with any worries you have, and help to give any practical help you need.
- You can call our helpline on **0303 303 0303** or email patientinfo@anthonymolan.org. Our opening hours are 9am to 5pm, Monday to Friday (excluding bank holidays).
- The **Sickle Cell Society** supports and represents people with sickle cell disease. You can find lots of information and advice on their website: sicklecellsociety.org
- The NHS also has information about sickle cell disease, including symptoms, treatments, and living with sickle cell disease, on their website: nhs.uk/conditions/sickle-cell-disease



Scan this QR code with your phone's camera to find more information and support on this topic on our website.



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Sickle cell and stem cell transplant

If you have been told that a stem cell transplant may now be a treatment option for your sickle cell disease, you might have lots of questions. There is a lot to think about and consider.

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 anthonymolan.org/sicklecell

Remember: Your healthcare team will know your unique medical situation best, but this information will help guide you through this potentially tricky process.

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

Yes, you might now be able to have a stem cell transplant to cure your sickle cell disease. This treatment 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 anthonymolan.org/understanding

You are likely to only be offered a stem cell transplant if the benefits outweigh the risks. In this case, you may have severe sickle cell disease 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 don't work properly), acute chest syndrome (a lung condition causing chest pain and breathing difficulties), and infections
- puts you at risk of death.

Important: You can only have a stem cell transplant if you have a matched related donor – a brother or sister who is a full match and can donate their stem cells to you.

What are the risks and benefits?

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

Benefits

- A stem cell transplant can **cure** your sickle cell disease.
- You can expect your **pain episodes to stop**, but this may take some time. You might experience chronic pain due to the effects of your sickle cell disease. Your pain management will be carefully controlled 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 disease, like problems with your eyes and organ dysfunction.
- You can have a **better quality of life**. You may be offered a transplant if your severe sickle cell disease affects your day-to-day life and you don't respond well to any other treatments.



I've lost so much because of my sickle cell disease. I decided to have a stem cell transplant because I won't have to restart my life every time I have a crisis. I can restart my life for good.

Ronke, who had a successful stem cell transplant to cure her sickle cell disease in 2022



Search for 'Ronke Dosumu' on YouTube to watch Ronke's vlogs on her sickle cell and stem cell transplant journey.

Risks

- Any **current complications you have from your sickle cell disease**, 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 won't always be life-threatening and the risk of GvHD is much lower for people with sickle cell disease. 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 which lessens the risk of complications. Currently, for people with sickle cell disease, 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 disease. You may still need treatment for these complications after transplant.