



# TRANSFUSION PATHWAY

For people living with Sickle Cell Disorder



[www.togetherwecan.uk](http://www.togetherwecan.uk)



# TRANSFUSION STAGES



## What is a transfusion programme and why may it be considered

- There are 2 main types of blood transfusion: a simple top up which may involve 1 or 2 units of blood or an exchange blood transfusion where your blood is removed by a machine at the same time as non-sickle blood is given to you
- Repeated chest crises, painful crises or suffering from the effects of low haemoglobin, without sufficient improvement on hydroxycarbamide, or in patients for whom hydroxycarbamide is not an option

- A history of stroke/s or a raised Transcranial Doppler result/s
- You should have the opportunity to discuss any concerns you may have about being on a transfusion programme with your medical team

## Make sure each of these points is covered at your clinic appointment

- You should be listened to and a joint decision made by you and your medical team
- You should get the chance to explore your thoughts and feelings about transfusions

- You should be aware of the other treatment options available and given time to reflect on these
- You should be informed of the expected short and long term benefits, and potential risks associated with different types of transfusion programmes
- You should expect someone to take time to detail the practicalities and time commitment involved
- You should get the opportunity to discuss any concerns you may have about being on a transfusion programme with your medical team



## Blood Tests

### Are there any barriers to proceeding?

#### Checks prior to starting a transfusion programme

- You should visit the day unit or the transfusion unit for a vein assessment
- If your veins are tricky, someone should discuss the alternatives with you
- You will have blood tests to check for viruses and to enable close matching of transfused blood

#### In the 72 hour prior to transfusion

- You will be asked to come for a blood test a few days before transfusion

### The week before transfusion

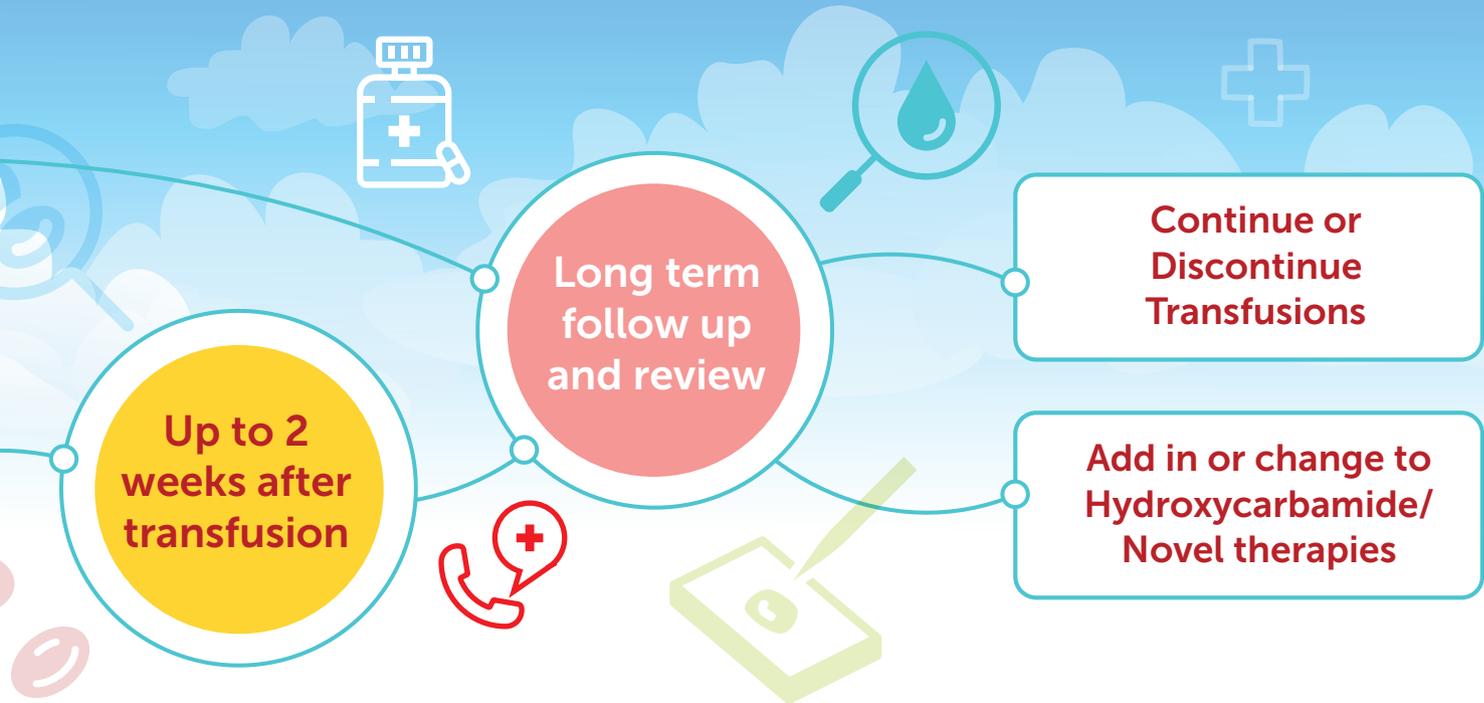
- You may be required to pause any blood thinners in the day prior to transfusion. Your medical team should discuss this with you

#### On the day of transfusion

- You should expect the person inserting the needle to do so with the minimal number of attempts, but it may not always be possible
- The nurses will monitor you closely during the transfusion, and explain what is happening at each stage

### Transfusion day

- You should be prepared to be in hospital for up to 8 hours so bring things with you to keep you entertained. You may find activities that keep your hands free are easier
- The availability of staff or blood can slow things down, but you should expect delays to be minimised
- The solution that keeps the blood flowing around the machine used for exchange transfusions can lower your calcium levels and make you feel dizzy. Please let your nurse know and they can supplement your calcium levels



## Up to 2 weeks after transfusion

- On the day of your transfusion a member of the team should always explain any possible side effects you may experience in the days after your transfusion prior to you going home

### Up to two weeks after transfusion

- You must contact your medical team if you feel unwell, have a fever or develop yellow eyes or skin as this may suggest a reaction to the blood
- Keep a diary of how you feel after the transfusion so you can review its effects with your medical team

## Long term follow up and review

### Long term follow-up whilst on a transfusion programme

- You and your medical team will regularly review your progress whilst on the transfusion programme. Sometimes small adjustments can make a big difference
- You will have your blood count and iron level monitored every 3 months
- You should be offered psychological support alongside medical care

**Continue or Discontinue Transfusions**

**Add in or change to Hydroxycarbamide/ Novel therapies**

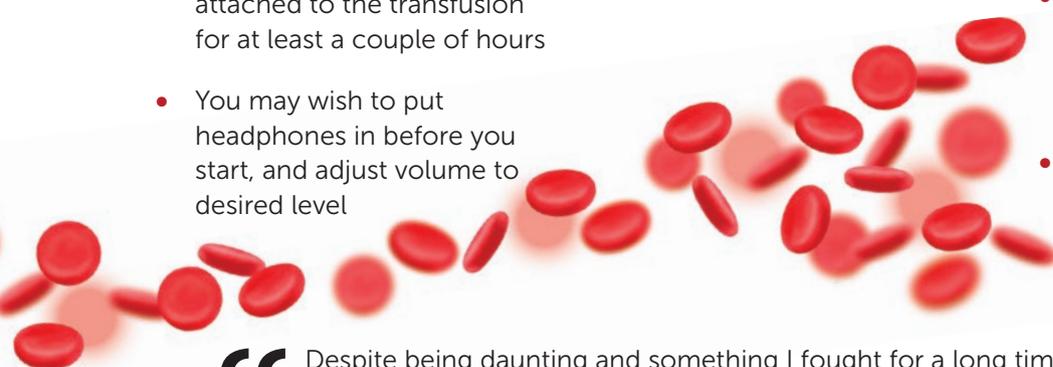
### High iron related to being on the top up transfusion programme (Ferritin > 1000)

- You will have an MRI scan of your liver and heart every 6-24 months depending on how high your iron levels are
- You may be started on medication (chelation) to bring your iron levels down



## TOP TIPS

- It's natural to have a range of feelings about starting on a transfusion programme, please do share these with your medical team
- Try as much as possible to hydrate well the day before your transfusion, aim for 3 litres or more. Some people having exchange transfusions like to drink milk to supplement their calcium levels
- Eat and use the toilet beforehand as you will be attached to the transfusion for at least a couple of hours
- You may wish to put headphones in before you start, and adjust volume to desired level
- Watching tv or listening to an e-book are good distractions, as these keep your hands free
- Ensure you have everything you might need/want close by before your transfusion starts i.e: headphones, food, book etc
- If your veins are tricky, ask for a heat pad (if available) before needle insertion. Some hospitals may use warm water instead. This makes your veins more visible
- You may feel tired/weak or have sickle type pains after your transfusion, this may last a few days and is to be expected. If it lasts longer, you feel unwell or the pain cannot be managed, let your medical team know
- Have a snack during (if possible), or shortly after before you go home
- If possible, arrange for someone to pick you up and take you home
- Dressings are best removed in the shower the day after, or ask for/buy dressing removal spray
- You may feel wiped out the next day. If possible plan for a light day'



“ Despite being daunting and something I fought for a long time, having exchange transfusions allows me a better quality of life, reduced frequency and severity of hospital admissions and a fighting chance at life when things take a turn for the worse, Absolutely grateful and blessed to be able to access this treatment. ”



# CONGENITAL ANAEMIA NETWORK

We are a group of patients, carers, doctors, and scientists who are all interested in patients with rare inherited anaemia.

This guide can be used to guide starting a simple transfusion (bags of blood) programme or an exchange transfusion programme.



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