

The logo consists of the words "Yes we can" in a white, rounded, sans-serif font, centered within a red circle that has a yellow border. The background of the entire image is a bright yellow sky with white, fluffy clouds and a few small birds flying. Below the sky, there are green rolling hills with yellow and orange trees, suggesting an autumn setting. In the foreground, a woman with long black hair, wearing a white long-sleeved shirt and an orange skirt, is holding a large orange cardboard box with a white cross on it. A man with short black hair, wearing a blue long-sleeved shirt with a white cross on the sleeve and dark pants, is also holding the box. Behind the box, there are several blister packs of pills: one with blue pills, one with white pills, and one with red and white capsules. The overall scene is bright and positive, representing medical support and care.

Yes we
can

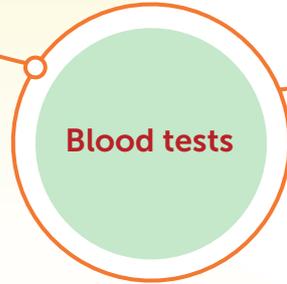
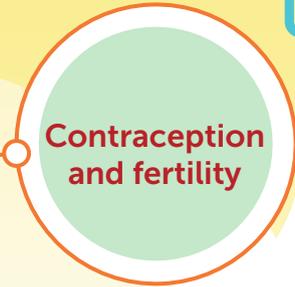
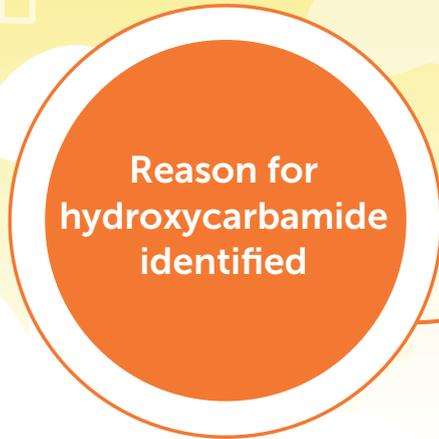
HYDROXYCARBAMIDE PATHWAY

For people living with Sickle Cell Disorder

www.togetherwecan.uk



TRANSFUSION STAGES



Why hydroxycarbamide may be considered:

- Severe/frequent chest crises or painful crises
- Long-term sickle pain
- Unable to have a blood transfusion programme
- Complications of sickle e.g. protein in the urine
- Improve life expectancy
- Reduce long term complications/organ damage

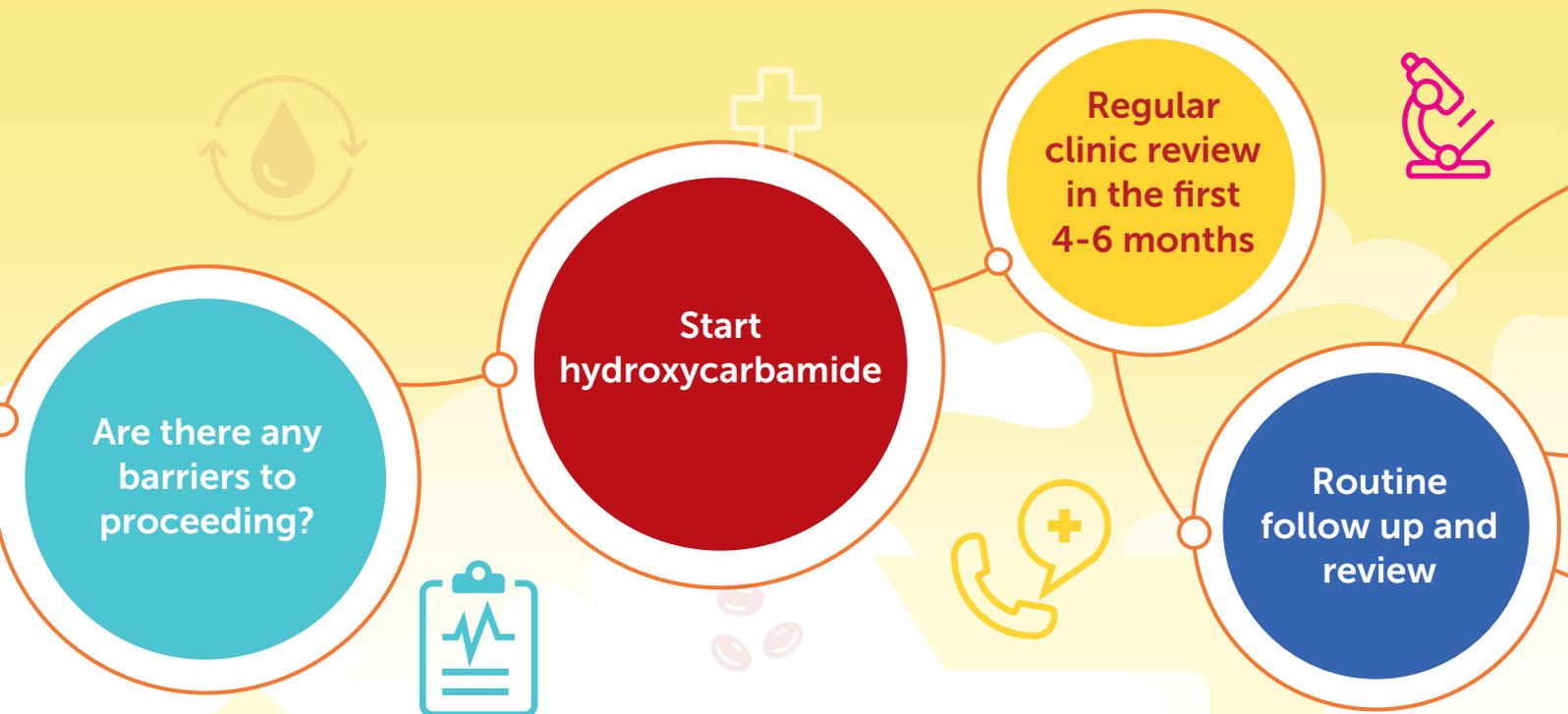
Make sure each of these points is covered at your clinic appointment:

- Your views should be listened to and a joint decision made by you and your medical team
- Your medical team will clearly outline the evidence for how hydroxycarbamide works, how it may help you and any potential side effects

- You should get the chance to explore your thoughts and feelings about hydroxycarbamide
- You should have an opportunity to discuss any other treatments available to you and be given time to consider your options

Checks to be done prior to starting on hydroxycarbamide

- You should be advised of the need for contraception whilst taking hydroxycarbamide. The possible options should be discussed with you
- Sperm analysis and sperm storage should take place prior to starting hydroxycarbamide
- You will have a blood test to check your baseline kidney and liver function as these will need to be monitored whilst you are on hydroxycarbamide



Are there any barriers to proceeding?

Start hydroxycarbamide

Regular clinic review in the first 4-6 months

Routine follow up and review

Starting hydroxycarbamide

- You should be given clear contact details for your medical team in case of problems
- Hydroxycarbamide is usually taken as a once a day tablet/capsule(s). Your starting dose will be based on your weight. A member of your medical team should go through in detail how to take hydroxycarbamide and how best to store it at home
- A plan should be agreed between you and the medical team for the best way of getting regular blood tests done to monitor your blood counts, liver and kidney function whilst taking hydroxycarbamide
- It may take a number of months after starting hydroxycarbamide for you to start to notice an improvement in you sickle symptoms

Side effects

- There are some potential side effects of hydroxycarbamide you should look out for and it would be important to contact your medical team if you have any concerns:
 - **Common side effects**- stomach upset (tends to settle), rash, darkening of the skin/nails, hair loss, mouth ulcers
 - **Uncommon side effects**– infections, abnormal kidney and liver tests, bleeding/bruising, skin ulcers
 - This information should also be provided in a more detailed written form either by paper or email



Continue with hydroxycarbamide

Stop hydroxycarbamide and consider other treatment options

Continue hydroxycarbamide with the addition of other treatments

Transfusion/Novel treatments

Intensive follow up (just after starting hydroxycarbamide)

- After you start hydroxycarbamide, the dose will be increased over a period of weeks to months with the aim of increasing the level of fetal haemoglobin measured in the blood but not reducing your blood counts (haemoglobin, white blood cells and platelets) too much
- You will be asked to have a blood test two weeks after starting hydroxycarbamide and then after every dose change. You should be informed of the results and any suggested changes
- Any changes to your blood count will be identified by your blood tests. If one or more of your blood counts drops too low, the hydroxycarbamide may be paused and/or restarted at a lower dose

Routine follow up (once you are on a stable dose of hydroxycarbamide)

- You will be asked to have a blood test every 2-3 months
- If you or your partner are planning a pregnancy it is important you speak to your medical team as early as possible. Your hydroxycarbamide will need to be stopped and an alternative medical plan will need to put in place for you
- If you find out you are pregnant whilst on hydroxycarbamide you must contact your medical team immediately. It will be suspended and an alternative plan put in place
- Your progress with hydroxycarbamide will be reviewed at each hospital appointment along with the need for additional treatment alongside hydroxycarbamide or the need to discontinue it



TOP TIPS

- You must follow the plan you and your medical team have made if you become unwell or develop a fever
- Hydroxycarbamide is used for other medical conditions including blood cancers. It has also been found to be a good treatment for sickle cell disorder. Please do not be alarmed if you find reference to its other uses online
- There is no evidence that hydroxycarbamide increases the risk of those with sickle cell disorder developing cancer over time
- Hydroxycarbamide can take time to work
- If you are struggling to take the tablets/capsule please speak to your medical team as other forms of hydroxycarbamide may be available
- If you forget to take your dose of hydroxycarbamide, take it as soon as you remember, the same day. If you remember the next day, do not double the dose, just continue with your normal prescribed dose and update your medical team if you are struggling to take it regularly
- Keep the tablets/capsules somewhere secure, out of the reach of children or pets
- Most vaccines are fine to have whilst on hydroxycarbamide, however, some live vaccinations may be less appropriate. It is important to let the vaccinator know you are on hydroxycarbamide so they can assess if it is safe for you to have the vaccine
- Whilst taking hydroxycarbamide, your skin may be more sensitive to the sun. It is therefore important to protect it by using sunscreen on exposed skin each day



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Even though I was initially reluctant, taking hydroxycarbamide has been revolutionary. It has enabled me to do things I couldn't do before such as sport, study and have more of a social life. I've had to be mindful though that I have to be consistent with taking it to get the benefits. Pick a part of your daily routine to fit it into. It's also worth being aware that when changing doses more blood tests are needed and there may be some stopping and starting of treatment depending on the blood results. This has always been closely monitored by the medical team and is a normal part of the process and to be expected.

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CONGENITAL ANAEMIA NETWORK

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

www.togetherwecan.uk

