



Hydroxycarbamide

Information for Parents/Carers

- As part of your child's treatment for sickle cell disease (SCD), they have been prescribed a drug called Hydroxycarbamide.
- **It is very important that your child is closely monitored when they are taking this medication.**
- This is to make sure that your child is on the correct dose.
- It is also **very important that you give the prescribed medication correctly**, whether it is in tablet or liquid form, so that your child can have the full benefit.

What is Hydroxycarbamide?

- Hydroxycarbamide is regularly used in the treatment of different blood disorders.
- Hydroxycarbamide is used for all children and young people with sickle cell disease (HbSS and HbSBeta0) from 9 months old.

How does Hydroxycarbamide work?

- Hydroxycarbamide increases the production of foetal (baby) haemoglobin in your child's blood. This can reduce the sickling episodes that your child may experience, by stopping the sickle haemoglobin from sticking together. This can take some weeks/months to take effect.
- It reduces the white blood cell count (neutrophil), which is often raised in people who have severe sickle cell disease. This may be important because the white cells produce chemicals, which can cause inflammation (swelling) and might speed up sickling. Having fewer of them makes this less likely.
- By taking this medication it is hoped that your child will have fewer, less severe, and less painful episodes.
- This will mean that your child will feel better and might experience less visits to the hospital, for long periods of time. Your child will be able to spend more time at school or with friends, doing the things that they enjoy.

How does your child take it?

- Hydroxycarbamide comes in a liquid (for children) or a capsule and is taken by mouth. Treatment begins on a low dose, daily, usually at:

20mg/kg in a child

0.5g (one capsule) or 15mg/kg (rounded up to the nearest capsule) in an adult.



- The dose will be gradually increased every two to three months, until the right dose is achieved.
- This will be the dose that gives them the most benefits without side effects.
- The decision will be based on symptoms and blood test results.
- The blood tests are done 2 weeks after starting the medication. Then, depending on your child's result, blood tests will be done more or less frequently.
- This process may take several weeks to complete. After this your child will need blood tests done every three months.
- If your child experiences any unwanted side effects or something shows up in the blood tests, the Hydroxycarbamide may be stopped, or they may be given a lower dose.

Parents who are unwilling for their child to be monitored regularly will not be eligible to use Hydroxycarbamide.

Giving my consent (permission)

- If your child is under 18 years of age and you agree for them to take Hydroxycarbamide, you will need to sign a consent form.

What to expect

- Most patients are well and have very little or no side effects.
- **It is important that you do not stop giving your child the Hydroxycarbamide.** It may take a couple of months before they reach the right treatment dose and can benefit from the effects of the medication.
- Hydroxycarbamide can occasionally make patients feel sick or be sick, cause skin rashes, hair loss, diarrhoea, liver damage, weight gain, and if the blood count drops significantly, infection or bleeding. It may also cause darkening of the nails.

Risks

- If your child has a temperature over 38°C you should contact the team (details below) to arrange for your child to have a blood test at the hospital urgently.
- Many people ask if Hydroxycarbamide increases the risk of cancer. We all have a risk of developing cancer during our lifetime.
- Some medications increase this risk a little, and this is true of a few medications which work in a similar way to hydroxycarbamide.
- There is **no evidence** that the risk of cancer is increased in patients with sickle cell disease who take Hydroxycarbamide, and we now have 20 years of evidence to support this.



- **Fertility** - There is evidence that suggests that Hydroxycarbamide can lower the sperm count of young men. However, it does increase again when they stop taking the medication. It is currently unclear about the effect on pre-pubertal boys.
- Males on Hydroxycarbamide can be offered sperm cryopreservation above the age of 14 years, usually completed when they are 17-18 years of age.

Please note that if your child experiences a sickle cell crisis with pain, even severe pain, you must continue to give the hydroxycarbamide.

Contact details

Children's clinical nurse specialist: 020 7288 3017 / 07799 347 161

Patient advice and liaison service (PALS)

If you have a compliment, complaint or concern please contact our PALS team on 020 7288 5551 or whh-tr.PALS@nhs.net

If you need a large print, audio or translated copy of this leaflet please email whh-tr.patient-information@nhs.net. We will try our best to meet your needs.

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