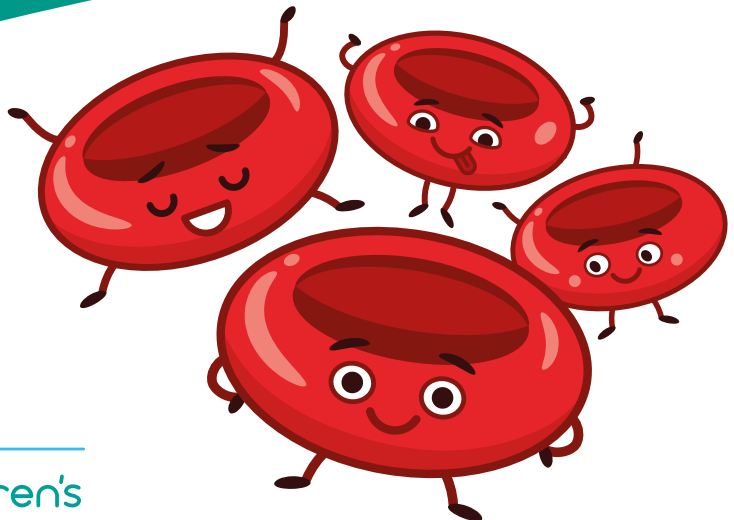


Hydroxycarbamide (also known as hydroxyurea) Use in sickle cell disease

Information for parents
and young people



Why have I been given this leaflet?

You have been given this leaflet because your / your child's haematology doctor thinks that starting a medicine called hydroxycarbamide will help reduce or prevent unpleasant complications of sickle cell disease.

What is hydroxycarbamide?

Hydroxycarbamide is a medicine that has been used to treat different blood disorders for many years. More recently, it has been used in sickle cell disease. Research studies have shown that it is effective in reducing symptoms associated with sickle cell disease. This evidence is so strong that the guidelines for treating sickle cell disease now recommend the use of hydroxycarbamide in a number of situations.

What does hydroxycarbamide do?

Two very large research studies have shown that taking hydroxycarbamide may have the following positive effects:

- A longer pain free period after starting treatment.
- Even longer period before the next painful episode.
- Fewer episodes of chest crises / sickle lung.
- Fewer blood transfusions.

How does hydroxycarbamide work?

It appears to work in three ways:

1. It increases the amount of foetal haemoglobin in the blood. It is known that a higher amount of foetal haemoglobin can protect against complications of sickle cell disease.
2. It reduces the “stickiness” of young red blood cells making them less likely to stick to the walls of blood vessels. This reduces the risk of a sickle cell crisis occurring.
3. It reduces the number of white blood cells and platelets in the blood. Both of these are often raised in people with sickle cell disease. Raised white blood cells and platelets increases the risk of painful crises.

Unlicensed medicines

Because hydroxycarbamide has been used for a long time for different blood disorders, not all brands of hydroxycarbamide are licensed for sickle cell disease. Some are marketed for other conditions. You may notice that the leaflet that comes in the box with your medication does not always contain information on sickle cell disease or giving hydroxycarbamide to children, this is another reason you have been given this leaflet. We know from the research studies that hydroxycarbamide is a useful medicine for treating sickle cell disease and you / your child will have been prescribed the product your doctor & pharmacist think will be best for you. If you want any more information on unlicensed medicines, please ask your doctor, nurse or pharmacist.

How do you take hydroxycarbamide?

Hydroxycarbamide is a medicine that is taken by mouth. It comes in liquid and tablet form. Your nurse, doctor or pharmacist will help you decide which preparation is best for you. It should be taken once per day and where possible, at the same time, every day. If you / your child forget to take a dose, it can be taken up to 12 hours late.

A double dose **must never** be taken if you / your child miss a dose. If this happens, just make a note of the missed day and let your doctor or nurse know at your next appointment.

Will I / my child need to have blood tests?

Yes. There is a small chance that taking this medicine can affect you / your child's blood cell count and liver function. To ensure no harm comes to your / your child, blood tests are taken at the following times:

- Every time the dose is changed. This might be as often as every two weeks until the right dose is found.
- Routinely, every 8 weeks. Your doctor does this to make sure your / your child's blood counts are not dropping below a safe level.
- If the blood counts drop too low or there is a problem with liver function, a blood test will be taken every week until these have got better.

Are there known side-effects?

A small number of people have reported the following side-effects:

- Sickness
- Diarrhoea
- Weight gain
- Hair loss
- Skin rashes
- Drop in blood counts
- Liver damage
- Infection
- Bleeding

Most of these are uncommon. If you are concerned, you should discuss the risk to yourself / your child with your haematology doctor or nurse.

There may, sometimes, be other side-effects that are not listed above. If you notice anything unusual and are concerned, contact your hospital doctor, nurse or pharmacist.

When should I seek urgent medical attention?

You should let your haematology nurse or doctor know straight away if you / your child develop any of the following symptoms:

- A high temperature.
- Bruising or bleeding that cannot be explained (you / your child does not remember injuring themselves).
- A petechial rash (this looks like tiny red “pinprick” dots).
- If you / your child become unusually pale and feel very tired.

Informed consent

Before your / your child’s doctor can give you the hydroxycarbamide, a consent form must be signed by a parent or young person if over the age of 16.

Contraception

Young people who are sexually active must agree to use contraception while taking hydroxycarbamide. This is because the effect of the medicine on unborn babies is not yet known.

Future fertility

Some small research studies have shown a drop in sperm count in adult males taking hydroxycarbamid; however, the following is not yet clear:

- Whether the drop in sperm count affects the man's ability to have children.
- Whether the sperm count returns to normal when the man stops taking hydroxycarbamide.

Hydroxycarbamide should be avoided by males and females who are planning to start a family.

The haematology doctors will discuss fertility, sperm bank collection and birth control with teenagers and young adults.

The haematology doctors, nurses and pharmacists will be very happy to discuss any of these issues with you.