******

Haematology Department

**Sickle Cell Disease – Taking Hydroxycarbamide**

Information for parents and carers

**Introduction**

This leaflet is designed to explain about taking a medicine called Hydroxycarbamide. Your child has been prescribed Hydroxycarbamide by their Sickle Cell Team. This leaflet will explain how to take it, what monitoring will be required and what to look out for in your child.

**How is Hydroxycarbamide taken?**

****Hydroxycarbamide comes as either a liquid or tablet that is taken once a day, every day. The amount that your child is given depends upon their weight, and how well they respond to it. Some children need a low dose to give them benefit, others need a high dose. The dose your child is started on will be low, and this will be gradually increased by your Sickle Cell Team over a number of months.

**What should I do if I forget to give my child their Hydroxycarbamide?**

If you forget to give hydroxycarbamide to your child one day - do not give them a double dose the next day.

**What will happen if I don't give my child their medication every day?**

For Hydroxycarbamide to work and to reduce the symptoms of sickle cell it needs to be taken every day, roughly at the same time of day. Missing even one dose will reduce the effect and increase the chances of your child having a sickle cell crisis.

It is very important to encourage your child to take Hydroxycarbamide every single day. Children often have difficulties taking medications, or you may have trouble remembering to give it every day. If this is the case, tell your Sickle Cell Team they will help you come up with ways to help your child take Hydroxycarbamide every day.

**Where should I keep my child's medicine?**

Your child's medicine should be kept in a cupboard out of reach from children. Keep tablets in the packaging until you need to give it to your child.

**Where should I get more of my child's medicine from?**

You need to get Hydroxycarbamide from the Hospital. You cannot get it from your GP or local pharmacy. Make sure you ask for more medication from your Sickle Cell Team before your current supply runs out.

**How will my child be monitored for side effects?**

The commonest side effects from taking Hydroxycarbamide are on the blood. It can reduce the haemoglobin, platelets and white cell count. To monitor for these side effects your child will have a blood test every two to four weeks.

**What symptoms will my child have if they are having side effects from Hydroxycarbamide?**

* **Low haemoglobin:** Increased tiredness

Paleness

Headaches

Breathlessness

* **Low platelets** Increased bruising

Nose bleeds

Gum bleeding

Rash of red / purple spots

* **Low White cells** Increased infections

Mouth ulcers

**What should I do if I notice any of these symptoms?**

If you notice any of these symptoms then contact your Sickle Cell Team for advice. They will recommend that you bring your child to hospital for a blood test.

**What will happen if my child's haemoglobin, platelets or white cells are low?**

If your child's blood levels have reduced to an unsafe level your Sickle Cell Team will recommend that your child stops taking Hydroxycarbamide for a short period of time. Your child's blood levels will quickly return to their normal level. Your child will have blood tests done again until they have returned to normal. They will then restart Hydroxycarbamide again at a lower amount than before.

**Further information**

If you have any questions or want any further information please contact your Sickle Cell Team on 0151 252 5070.

**Useful websites**

[www.alderhey.co.uk](http://www.alderhey.co.uk)

[www.sicklecellsociety.co.uk](http://www.sicklecellsociety.co.uk)

Alder Hey Children's NHS Foundation Trust is neither liable for the contents of any external internet site listed, nor does it endorse any commercial product or service mentioned or advised on any of the sites.

****This leaflet only gives general information. You must always discuss the individual treatment of your child with the appropriate member of staff. Do not rely on this leaflet alone for information about your child’s treatment.

This information can be made available in other languages and formats if requested.

****Alder Hey Children’s NHS Foundation Trust

Alder Hey

Eaton Road

Liverpool

L12 2AP

Tel: 0151 228 4811

[www.alderhey.nhs.uk](http://www.alderhey.nhs.uk)

**© Alder Hey Review Date: April 2024 PIAG: 0073**