

Classical homocystinuria

explained to children





What is homocystinuria ?

You have a very rare problem, called **homocystinuria** (HCU for short).

When we eat, our bodies **break down the food**. **Homocysteine** (HC for short) is made when some foods are broken down. In most people, HC is **broken down further**. Your body **cannot break down HC**, so **HC builds up** and it **can cause problems**.

Fortunately, the **treatment** you are on can prevent problems.

Is homocystinuria contagious ?

No homocystinuria is **not contagious** like the flu or the chickenpox. You can go to **school** and **play with your friends** without any problems.



Are there other children with the same illness ?

Although your illness is rare, you are not the only one who has it !

Other boys and **girls** all over the world also have it.



Am I different from everybody else ?

Everyone is **different**. There are no two persons in the world that are exactly the same. Some children are tall, some are small and your best friend might have brown hair or be blond... **You are just who you are !** You have an illness that few other people have, but it can be treated.





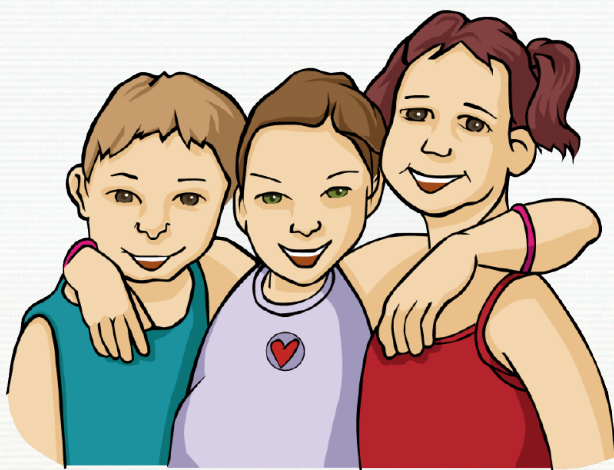
Can I continue to go to school and on vacation ?

You may feel you are different. But if you take your **treatment** regularly you can **go to school** and **on holiday** ; And **go to parties** like other children

Do other people need to know ?

It is up to you whether or not to tell your friends. It is usually best to **tell your good friends** that you've got a medical problem, so they understand why you need a special treatment.

It is probably best that your **school teachers** know that you have this problem and your parents will probably talk to them about this.



When I grow up, will I still have this disease ?

Your disease will **not go away** like chickenpox does. You will have your disease all your life and will always have to continue **treatment**. This sounds like bad news, but this is better than feeling sick and unwell, isn't it ?

If you take your treatment regularly and follow the diet as recommended by your doctor, you can have a job and a family like everybody else when you grow up.

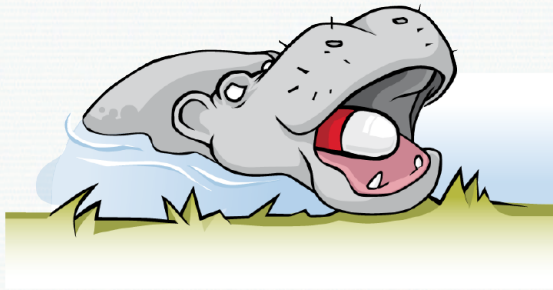
Why do I have to see my doctor regularly ?

You have to see your **doctor** regularly to **make sure that all is well**. The doctor needs to check that your treatment is working and this is why he keeps doing **blood tests**.

When you see your doctor, you can also tell him how you feel and **ask** any **questions** you may have.

Will I have to take medicines ?

You will have to **take your medicines regularly** and you will need to do this forever. If you take your medicines correctly, you will remain able to do all the fun things you are doing today ! And taking medicines is much better than getting sick, isn't it ?



Can I eat what I want ?

Some children with your disease have to follow a **special diet**.

Your doctor will tell you whether you **need a special diet or not**.



What happens if I stop taking my diet and eat things I am not supposed to ?

In the beginning, you won't feel ill but **harmful substances** will build up in your body.

After a little while, these would **cause serious problems** and you may need to come into hospital for special medicines.

Without treatment, homocystinuria can cause problems with learning, eyesight, the skeleton and blood dots.



This leaflet arises from the project E-HOD which has received funding from the European Union, in the framework of the Health Programme

For more information :

http://ec.europa.eu/health/programme/policy/index_en.htm

For more information <http://www.e-hod.org>