

Endocrine Problems in Thalassaemia

Information and advice for patients

Sickle Cell & Thalassaemia Centre Diabetes & Endocrine Unit

What is Thalassaemia?

Thalassaemia is a genetic disorder affecting the function of the red blood cells leading to chronic anaemia. Patients with thalassaemia need regular blood transfusions.

Why do I get endocrine (hormone) problems in Thalassaemia?

The frequent blood transfusions can cause accumulation of iron in the body. Both chronic anaemia from thalassaemia and the excessive iron levels can affect the many endocrine tissues such as the pituitary gland (the master gland in brain).

What endocrine problems am I more likely to get in Thalassaemia?

The commonest endocrine problems are failure to grow and fertility problems. Other endocrine problems are:

- Underactive thyroid - inadequate functioning of thyroid gland
- Diabetes mellitus - when you have high sugar levels in your body
- Delayed puberty and fertility issues (difficulty conceiving)
- Osteoporosis (brittle bones)

A brief description for each of the condition above will be covered in this leaflet.

Underactive thyroid or Hypothyroidism

Your thyroid can become underactive and this condition is called hypothyroidism. If you have hypothyroidism, you may suffer with tiredness, weight gain or constipation. Your doctor will be monitoring your thyroid function (a blood test) if you have had iron transfusion for 3 or more years. If you have hypothyroidism, it is easily treated with thyroid tablets, a medication by the name of levothyroxine.

Diabetes Mellitus

Diabetes mellitus is a condition when you have high sugar levels in your body. This happens when your pancreas fails to release sufficient insulin to reduce the sugar levels. High sugar levels can cause weight loss, increase in thirst, increasing frequency of urination or vaginal infections. The test for diabetes mellitus will be a test called oral glucose tolerance test (OGTT).

If you have diabetes, it is important that you do finger prick glucose tests regularly at home and record them down. You also need to take your diabetes medications/insulin regularly.

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If you have any problems with your diabetes, you will also need regular appointments to review your diabetes control with a specialist doctor or a diabetes specialist nurse.

Delayed Puberty and Fertility Problems

In some young men, testicular enlargement may be delayed. Similarly, in some young women, there may be absence of breast development or absence/infrequent menstrual periods. This is due to a condition called hypogonadism. In young men, it is because of a lack of male sex hormone testosterone, whilst in women, it is because of a lack of oestrogen in the body.

This condition can be picked up from a blood test. In young men, this can be treated with testosterone replacement. Likewise, in young women, oestrogen replacement in the form of oral contraceptive pill will help.

In some cases, a female patient with thalassemia might have period and fertility problems and difficulty conceiving and may need assisted fertility treatments such as in-vitro fertilisation (IVF). Your GP can refer you to the fertility clinic at the Birmingham Women's Hospital.

Osteoporosis

Osteoporosis is a condition due to bone mineral loss and bones becomes less dense and more brittle. This makes you more susceptible to fractures if you have a minor fall. Osteoporosis can be diagnosed through a DEXA scan. DEXA stands for dual-energy X-ray absorptiometry. The X-ray department will use specific machines to check your bone density. You might be asked to take calcium and Vitamin D supplementations to prevent or treat osteoporosis. Your doctor might also prescribe other medications to protect your bones.

What if I have bone marrow transplant?

In some cases, bone marrow transplant early on may reverse some of the endocrine problems.

The Thalassemia-Endocrine clinic

This is a joint clinic runs by the specialists doctors and nurses in thalassemia and endocrinology (hormone specialist).

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Where and when is the clinic?

It is held every two month, from 9.30am to 12.30pm at the Sickle Cell & Thalassaemia Centre within the City hospital and an appointment letter will be sent beforehand. You will see both your Thalassaemia and Endocrine consultants. Your hormone results and diabetes will be reviewed to look for how well they are being controlled on current medications. You may need additional hormone tests and other specialist referral particularly for fertility issues. You will be asked to bring your blood sugar readings and this will be checked and alterations to your diabetes medication and insulin may be made. You will receive help and support from the diabetes specialist nurse in between appointments.

What can I do to minimise the risk of endocrine problems?

- **Iron chelation therapy (Removal of excess iron from body)**
Iron chelation therapy is essential to reduce your risk of excessive iron accumulating in the body and thus prevent endocrine problems. Examples of medications used for chelation therapy are desferal, deferasirox, deferirone and desferoxamine. If the doctor has recommended iron chelation therapy, this must be taken regularly.
- **Have regular annual endocrine tests and review in clinic.**

Endocrine tests

The annual endocrine tests usually involve blood tests to check for specific hormones. They are summarised below:

- Thyroid function test to check for underactive thyroid;
- Glycosylated haemoglobin A1c or oral glucose tolerance test to check for diabetes mellitus;
- Sex hormones such as testosterone or oestrogen levels;
- DEXA scan (Dual-energy X-ray absorptiometry) - to check for osteoporosis;
- Calcium and Vitamin D levels.

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Contact details

Sickle Cell & Thalassaemia Centre

City Hospital
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Birmingham
B18 7QH

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Further information for patients

UK Thalassaemia Society

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London N14 6PH

Tel: 020 8882 0011 Fax: 020 8882 8618

Website: www.ukts.org

The information in this leaflet is general and is intended to be a guide only. Please discuss the specific details of your treatment with your GP.

Sources used for the information in this leaflet

- UK Thalassaemia Society, 'Standards for the Clinical Care of Children and Adults with Thalassaemia in the UK', 2008
- Children's Hospital & Research Centre Oakland, 'Standards of Care Guidelines for Thalassaemia', 2012

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If you would like to suggest any amendments or improvements to this leaflet please contact the communications department on 0121 507 5303 or email: swb-tr.swbh-gm-patient-information@nhs.net



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