

The information in this pamphlet gives a brief overview of diabetes and its treatment, but patients diagnosed with diabetes are encouraged to obtain more detailed information from their health care provider or from the American Diabetes Association (www.diabetes.org).

For more information about thalassemia and diabetes, or about other issues involved with thalassemia care, talk with your health care professional, or contact the Cooley's Anemia Foundation (800-522-7222 or info@cooleysanemia.org) or one of the Thalassemia Centers of Excellence.

The Thalassemia Centers of Excellence have the most highly trained thalassemia experts in the country. They are located at:

Children's Hospital Boston
Children's Hospital Los Angeles
Children's Hospital Oakland
Children's Hospital of Philadelphia
Children's Memorial Hospital (Chicago)
Weill Medical College of Cornell University (New York)

Many other hospitals are satellite centers affiliated with these Centers. Please contact the Cooley's Anemia Foundation for a list of these satellite centers.



Published by the Cooley's Anemia Foundation, 330 Seventh Ave., #900, New York, NY 10001 www.cooleysanemia.org (800) 522-7222

This publication is made possible by an unrestricted educational grant from Novartis Pharmaceuticals.

The information in this publication is for educational purposes only and is not intended to substitute for medical advice. You should not use this information to diagnose or treat a health problem or disease without consulting a qualified health care provider. The Cooley's Anemia Foundation strongly encourages you to consult your health care provider with any questions you may have regarding your condition.

Thalassemia and Diabetes

by Dorothy Kleinert, RN and Craig Butler

Living with Thalassemia

Issues in Thalassemia Care

Some people with thalassemia develop diabetes, which adds another burden to managing their health. It is very important for people with thalassemia to do what they can to prevent diabetes and to follow their treatment plan should they develop diabetes.



What exactly is diabetes?

Diabetes is an endocrine problem, which occurs very frequently in the general population. The people most at risk for developing diabetes are those with a family history of diabetes and people who are overweight, who are not active and who have high blood pressure. The main cause of diabetes in people with thalassemia is iron overload in addition to these other factors and the presence of liver disease and viral infections, which are common with thalassemia.

Diabetes occurs when the body can no longer handle the way it deals with the sugar we get from the food we eat. Normally when we eat, the body changes the food into sugar (called glucose), which is sent into our blood stream. Insulin, a hormone produced by the pancreas, moves the sugar out of the blood and into our cells for energy.

In diabetes, the body either doesn't make enough insulin or it isn't able to use the insulin efficiently, causing too much sugar to stay in the blood and not be available for the cells to use for energy.

Diabetes is a serious disease that can cause eye damage and blindness, numbness or tingling in

feet, hands, or legs (neuropathy); heart and blood vessel problems; wounds that won't heal; kidney problems and frequent urinary tract infection; and problems with sexual relations.

There are two types of diabetes, Type 1 and Type 2; with both types there are problems with insulin and blood sugars.

With Type 1, the pancreas is no longer able to make insulin. This used to be called juvenile diabetes, because it occurred typically in young people but it can occur at any age when the cells in the pancreas no longer make insulin.



With Type 2, the pancreas can still make some insulin but in amounts insufficient to meet the needs of the body.

Some people have impaired glucose tolerance; their blood sugar levels are a little higher than normal, but they do not have diabetes and very often they have no symptoms. However people with thalassemia often do go on to develop diabetes if they do not adhere to their treatment plans.

How are glucose intolerance and diabetes diagnosed?

Impaired glucose tolerance is diagnosed by: a higher than normal fasting glucose level; a higher than normal glucose level on a blood test taken 2 hours after eating; and by an abnormal oral glucose tolerance test. Diabetes is diagnosed when these blood tests results are very abnormal and often the person will have some symptoms such as fatigue, extreme thirst, frequent urination and vision changes.

What is involved with testing for diabetes?

Annual oral glucose tolerance testing is recommended for all people with thalassemia after 10 years of age, who should be referred to an endocrinologist for testing and treatment should they need it. Oral glucose tolerance testing involves taking a sample of blood at various times both before and after the person has drunk a special glucose solution. The blood tests are done before they drink the solution, and 30 minutes, 60 minutes, 90 minutes and 120 minutes later. Total time is about 2 hours. Often, the person is required to fast (not eat or drink) from midnight the evening before the test.

How is diabetes treated?

Treating glucose intolerance involves making changes to one's diet, cutting down on carbohydrates and following an exercise program outlined by your treater. Losing excess weight is important in managing glucose intolerance, as is being compliant with your chelation. Some people may also need to take an oral medication and/or monitor their blood sugar levels. This is usually done first thing in the morning before eating (fasting morning glucose).



The management of diabetes is more involved. In addition to dietary changes, exercise, weight loss and good chelation, some thalassemia patients may respond to oral diabetic medication. However, the majority of patients with diabetes often need to administer insulin to themselves on a regular basis. The doctor taking care of your diabetes will develop a treatment plan to best manage the required type of insulin, the amount of insulin and how often you need to take the insulin. There are several types of insulin, and the dose and frequency of use varies depending on what type is prescribed for you. It is very important that you follow the treatment plan so that you don't have episodes of having blood sugars that remain too high (hyperglycemia), which cause problems in the long term, or blood sugars that are too low (hypoglycemia), which cause more immediate problems like feeling nervous or jittery.

What can I do to help prevent diabetes?

As with many other complications related to thalassemia, iron overload can play a part in the development of diabetes - so making sure you follow your chelation plan is very important.

Diabetes is a serious illness and its management is involved and can be time consuming; however, many people with thalassemia have successfully navigated the demands of handling these two problems. For advice and help, please contact CAF patient services and our patient support group, TAG (Thalassemia Action Group), and speak openly about adjusting to changes in your care with your nurses and health care provider.