I was diagnosed with thalassemia, but I don't know what it is [1]

Dear Alice,

I was discovered to have Thalassemia. Tried to check up on some health book but could not find complete description of what it is and the possible effects it may cause to my health. My doctor I consulted was not very clear either... please educate me more on this.

Answer

Dear Reader,

Thalassemia is a series of related genetic (inherited from your family) disorders of the blood that decrease the body's ability to produce hemoglobin - a part of red blood cells that carries oxygen and other vital nutrients throughout the body. The symptoms of thalassemia and their severity depend in part on whether a person gets the thalassemia gene from one or both parents.

Because this gene can be passed onto children, genetic counseling is recommended for people with minor thalassemia who are thinking about starting a family. The March of Dimes Resource Center [2] has additional information about genetic counseling, including how to find a site close to you.

People who receive the gene from only one parent have thalassemia minor. These individuals are known as trait carriers. Minor thalassemia often goes undetected because it poses no significant health problems. It can cause a mild form of anemia (a condition involving a decreased number of red blood cells that can cause fatigue) that does not respond to iron supplements, which is a common treatment for anemia.

People who receive a thalassemia gene from both parents have major thalassemia, which is also known as Cooley's anemia or Mediterranean anemia. Major thalassemia is most often treated by blood transfusions to keep hemoglobin levels high enough to transport oxygen. Without treatment, major thalassemia can have serious health consequences, including:

- Severe anemia
- Growth problems, including fragile and enlarged bones, facial malformations, and delayed growth
- Organ damage from iron deposits in the heart, liver, and pancreas
- Spleen enlargement
• Increased susceptibility to infection

Within the major thalassemia category are several different types of thalassemia that vary depending on the proteins that the person's hemoglobin lacks. Each type of thalassemia can have specific complications.

Because it sounds like your condition was identified in adulthood rather than in infancy or early childhood, it is likely that your form of thalassemia is minor (rather than major). Regardless, it is highly recommended that you consult with your health care provider. S/he may be able to refer you to a specialist in thalassemia. Only a health care provider can recommend what courses of action and/or treatment are appropriate for you.

Currently, there is no cure for thalassemia, but the Cooley's Anemia Foundation [3] is working to help educate people with thalassemia and ensure better access to treatment. The organization has a patient's advocacy group, as well as a discussion forum that can help people address some of their questions and perhaps identify a specialist in their area.

If your health care provider is still in the dark about this condition, you can email her/him this page, or print it for her/his reference. You learn something new every day!

Alice!
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General Health [4]
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