HOW ABOUT MY CHILD'S SOCIAL LIFE? HOW TO DEAL WITH FRIENDS AND RELATIVES?

Social interactions certainly differ among various societies and communities, as they are influenced by many different cultural, societal and religious factors. Unfortunately, it is not uncommon for people with physical disabilities to experience discrimination. Social stigma tends to be more intense in the context of small, rural communities and/or lower socioeconomic and educational level and in particular with regards to hereditary chronic diseases. Support groups formed by patients and parents can be of great help, as well as consulting experts (e.g. clinical psychologists). Neither hiding the condition nor overexposing it are considered healthy approaches. Parents and patients must first accept the condition and then communicate it properly to the people of their environment.

GETTING INVOLVED WITH YOUR LOCAL SUPPORT ASSOCIATION

Sharing experiences and joining other families in understanding the condition, making demands for service improvement where necessary, and educating the community to reduce prejudice are all functions of support associations that help families cope with conditions that sometimes seem overwhelming. For these reasons, parents are urged to become active members of their local thalassaemia association.

WHAT DOES TIF DO?

The Thalassaemia International Federation (TIF) is a non-profit, non-governmental organization that represents over 226 National Thalassaemia Associations from 66 countries across the world and is dedicated to supporting the equal access of every patient with thalassaemia to health, social and other care within patient-centered healthcare settings.

The Federation works in official relations with the World Health Organization (WHO) since 1996, in special consultative status with the United Nations Economic and Social Council (ECOSOC) since 2017, and in official partnership with the European Commission since 2018.

Its extensive **educational programme** includes a vast series of **internationally acclaimed publications** as well as **events, conferences, workshops, fellowships, etc.,** with the objective to provide **lifelong educational opportunities** for **health professionals, patients and their families,** raise awareness on thalassaemia amongst policymakers and the community at large, and **promote effective, disease-specific programmes** for the ***prevention, control and clinical management of thalassaemia within national healthcare systems based on universal coverage.***

For more information, you can visit
www.thalassaemia.org.cy

THALASSAEMIA INTERNATIONAL FEDERATION

THALIA

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THALASSAEMIA FOR PARENTS:

How Do I Care for my Child?

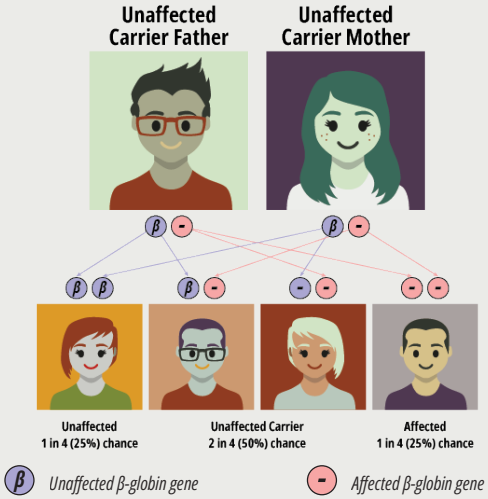
WHAT IS THALASSAEMIA?

Thalassaemia is a term used to describe a set of diseases that belong to a larger group, the anaemias. When someone has anaemia, his body cannot produce enough normal red blood cells, which are cells that carry oxygen from the lungs throughout the whole body. They flow in the blood stream and give it its red color. Thalassaemias are hereditary diseases, meaning that they are caused by problems within our genetic make-up, and not because of nutrition or other environmental factors, and are passed on to children from their two parents – both mother and father. What is at fault in thalassaemia is a change in the haemoglobin molecule, a protein found within each red cell, responsible for carrying oxygen to tissues and organs.

There are different types of thalassaemia, some of which require more demanding therapy than others. In any case, patients with thalassaemia must be followed by healthcare professional experts in specialized centers throughout their lifetime to have the best possible health outcomes.

HOW IS THALASSAEMIA INHERITED?

When both parents are "carriers" of the disease, in other words when they carry one affected gene related to haemogobin, this does not affect their own health. However, if the child inherits both affected genes (25% chance in each pregnancy), one from the mother and one from the father, they will have the full-blown disease – what we call *thalassaemia major* or *transfusion-dependent thalassaemia.* This disorder is more common in people originating from certain parts of the world, such as countries around the Mediterranean Sea and the Middle East (β-thalassaemia), through to Southeast Asia where malaria infection is (or was) endemic.



MY CHILD WAS DIAGNOSED WITH THALASSAEMIA. WHAT HAPPENS NEXT?

First of all, there is no need to panic! Thalassaemia can be treated very effectively nowadays, and patients can enjoy good quality of life, quite close to that of their peers. However, for that to happen, it is very important to follow medical advice by experts. You must find a specialized Thalassaemia Center close to you that will undertake the medical follow-up of your child as often as needed. A paediatric haematologist or a paediatrician with experience in thalassaemia should examine your child. Moreover, the Thalassaemia Center networks and collaborates with other specialized healthcare professionals across medical disciplines who will work to give your child appropriate care overall.

HOW IS THALASSAEMIA TREATED?

Patients with thalassaemia require regular blood transfusions once or twice a month (according to their needs) throughout their life. This usually happens in the specialized Thalassaemia Center that takes care of the patient. Transfusions may be needed regularly (usually once every 2–5 weeks) or occasionally (for instance during infections or pregnancy), depending on the severity of the disease. Because of lifelong transfusions, patients must take some medication daily (called chelation therapy) to remove iron, a substance that accumulates in the body when blood cells break down after a while following transfusion. This iron is very toxic to body organs, including the endocrine system (e.g. thyroid), heart, liver and others. Iron removing drugs (chelators) may be pills or syrups that can be taken orally or liquid solutions that must be injected slowly under the skin, in the abdomen or other parts of the body, over a period of several hours. Therefore, patients should be followed up on a regular basis by other experts, such as endocrinologists, heart and liver specialists, etc., to make sure that they grow as normally as possible, with no complications in vital organs.

WHY IS IT IMPORTANT TO FOLLOW TREATMENT?

Patients that receive proper treatment enjoy a very good quality of life and their life expectancy is not very different from that of the general population. However, when not treated properly, thalassaemia can have very serious complications on patients' health and even lead to premature death. Missing transfusion appointments and neglecting chelation therapy will make anaemia worse and will lead to accumulation of toxic iron in the body. Complications that may occur include growth retardation, darkening of the skin, feeling of weakness and "lacking energy", heart problems, spleen enlargement, deformities in the child's face, short stature, and other issues. Such complications develop gradually and sometimes, by the time symptoms become obvious, a lot of damage has already been done. This is why it is very important to follow treatment properly, as neglecting therapy may not give symptoms for a long time giving parents and children the false idea that no harm is done. Moreover, cultivating the culture of adherence to treatment and self-discipline will be helpful for the child throughout their whole life, especially in turbulent periods such as adolescence. In addition to that, keeping in good health is vital for benefiting from future therapies expected to change the landscape of the disease.

HOW DOES THERAPY INTERFERE WITH SCHOOL?

A child that has a severe form of thalassaemia, usually *thalassaemia major* or *transfusion-dependent thalassaemia,* will need to receive blood transfusions on a regular basis. In most cases, this interferes with school schedule, therefore being absent from school every few days or weeks may be the norm. To minimize the consequences of school absenteeism, parents will have to inform the responsible school personnel (teachers, principal, school nurse, etc.) about the situation, so that they will make sure that they can try to make up for lost teaching hours and be vigilant about any symptoms related to the disease that could appear while in school. All this should be done with both discretion and respect to the child's personality to avoid social stigma and discrimination through your local patient association. A patient-friendly transfusion regimen may be arranged, i.e. outside school hours.