

Haematology Department

Living with Thalassaemia

Information for parents and carers

What can a person living with Thalassaemia do to stay healthy?

A healthy lifestyle is important for everyone. For people living with thalassaemia, it is especially important to know that a healthy lifestyle means “managing the disorder”, as well as making healthy choices.

Managing Thalassaemia

Thalassaemia is a treatable disorder that can be well-managed with blood transfusions and chelation therapy. A person with thalassaemia will need to receive medical care on a regular basis from a hematologist (a medical specialist who treats diseases or disorders of the blood) or a doctor who specialises in treating patients with thalassaemia. If a doctor has prescribed either blood transfusions or chelation therapy, the most important thing a person with thalassaemia can do is stick to their transfusion and chelation schedules to prevent severe anemia and possible organ damage from iron overload, respectively.

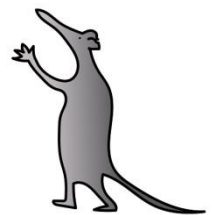
Healthy Choices for People Living with Thalassaemia

Other healthy choices a person with thalassaemia should consider include keeping vaccinations up-to-date, eating nutritious meals, exercising, and developing positive relationships.

Vaccines

Vaccines are a great way to prevent many serious infections. Children and adults with thalassaemia should get all recommended vaccinations, including a flu vaccination. People with thalassaemia are considered “high risk” for certain infections, especially if they have had their spleen removed, and should follow a special vaccination schedule for the following vaccines:

- Haemophilus influenzae type b (Hib)
- Pneumococcal vaccines
- Meningococcal vaccines
- Influenza – yearly



If you/your child are receiving blood transfusions as part of your/ their treatment, it is important to be vaccinated against hepatitis A and B. These are viruses that can be spread through blood.

Nutrition

Eating nutritious foods is important for everyone to maintain a healthy lifestyle – a diet, high in fruits and vegetables and low in fats is ideal for gaining the essential nutrients our bodies need. For people living with thalassaemia, because too much iron may build up in the blood, foods high in iron may need to be limited. Iron can be found in meat, fish, and some vegetables (e.g. spinach). Other products, like cereal and orange juice, may contain extra iron. Persons with thalassaemia should discuss with their doctor whether or not they should limit the amount of iron in their diet.

Exercise

Exercise is part of an overall healthy lifestyle and helps lead to better health outcomes. Although some people with thalassaemia may have trouble participating in vigorous forms of exercise, many people with thalassaemia can participate in moderate physical activities including biking, running, and walking. If a person with thalassaemia has problems with their joints, there are many kinds of low-impact activities to choose from including yoga, swimming, or water aerobics. If you have thalassaemia, you should discuss with your doctor the level of exercise that would be best for you.

What are the benefits of exercising?

The following are some of the benefits of regular exercise:

- Helps to improve and maintain good overall health.
- Strengthens the heart, lungs and blood vessels
- Increases muscle strength.
- Improves flexibility.
- Increases endurance and stamina.
- Increases natural pain killers (called endorphins) in the body's nervous system, which help control pain.
- Helps with weight control.
- Helps to improve quality of sleep.
- Reduces fatigue and increases energy.
- Helps to reduce stress, and depression.



Travel advice:

Most children with Thalassaemia are able to travel abroad providing they take appropriate precautions.

Before you travel – discuss your travel plans with your Specialist Nurse or Consultant to ensure your trip fits around any transfusion dates. They can also confirm if your child is well enough to travel and advise on any necessary precautions.

Make sure the travel agent, airline and insurance company are all aware of your child's diagnosis and medical condition.

It is advisable to make yourself aware of the medical facilities available in the country you are visiting and obtain contact details of a local treatment centre.

What to carry with you – a copy of a recent outpatient clinic letter or medical report from your Consultant or other member of the Haematology team, stating the diagnosis and treatment. This should include your latest Hb, medication doses, blood group and any allergies.

For insurance purposes you may need a letter to confirm that you are fit to travel.

Ensure you have enough medication to last the whole trip and a copy of the prescription. For air travel, the medicines should be packed in your hand luggage and a customs letter will be needed for suspensions, to explain why you are carrying liquids.

If you are travelling to a country within the European Economic Area (EEA) you are entitled to EMERGENCY healthcare at a reduced cost or free. To access this you need to obtain a European Health Insurance Card (EHIC) which is free of charge prior to travel. This can be requested in one of the following ways:

Online (<http://www.nhs.uk/NHSEngland/Healthcareabroad/EHIC>)

Telephone 0845 606 2030

Application form (available from post office)

Source:

<https://www.cdc.gov/ncbddd/thalassemia/living.html>

Further information

If you have any questions or want any further information please contact your Sickle cell Team on 0151 252 5070.

Useful websites

www.alderhey.co.uk

www.ukts.org

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This leaflet only gives general information. You must always discuss the individual treatment of your child with the appropriate member of staff. Do not rely on this leaflet alone for information about your child's treatment.

This information can be made available in other languages and formats if requested.

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