

So is it important for my partner to be tested?

Yes. It is very important if you are planning to have children.

Should any other members of my family be tested for thalassaemia?

Yes. Some of your children could have thalassaemia and they should be tested for it. Your brothers and sisters should also be tested particularly if they are planning to have children.

Where can they be tested?

A blood test for thalassaemia can be arranged through your family doctor/GP.



How do I find out more about thalassaemia?

For further information about thalassaemia please contact:

Thalassaemia Australia Inc.

333 Waverley Road, Mt Waverley VIC 3149

Ph: 03 9888 2211

Email: info@thalassaemia.org.au

Web: www.thalassaemia.org.au

Thalassaemia Services Victoria

Medical Therapy Unit, Monash Medical Centre

246 Clayton Road, Clayton VIC 3168

Ph: 03 9594 2756

Mercy Hospital for Women

Genetics

163 Studley Road, Heidelberg VIC 3084

Ph: 03 8458 4250

Royal Women's Hospital

Thalassaemia Clinic

Cnr Grattan Street and Flemington Road, Parkville VIC 3052

Ph: 03 9342 7000 Fax: 03 9342 7802

In NSW contact:

Thalassaemia Society of NSW

Level 7, King George V Building,

Missenden Road, Camperdown 2050

PO Box M120 Camperdown NSW 2050

Ph: 02 9550 4844 Fax: 02 9519 3517

Email: coordinator@thalnsw.org.au



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So you have BETA
Thalassaemia minor...

Important information for
you and your family

What is thalassaemia?

Thalassaemia is an inherited condition which affects the production of haemoglobin, the oxygen-carrying component in the red blood cells. It appears in two forms – thalassaemia minor (the carrier or heterozygous form) and thalassaemia major (the homozygous form).

How did I get it?

You inherited it: that is, it was passed on to you from one of your parents.

Will I always have it?

Yes. You were born with thalassaemia minor and you will always have it. It will not go away or change into thalassaemia major or any other condition. It is not contagious.

Will my health be affected?

No. Thalassaemia minor is a carrier state and does not seriously affect a carrier's health and no treatment is needed. However, any doctor you see should be told that you have thalassaemia minor as this may prevent unnecessary blood tests and treatments.

If thalassaemia minor does not affect my health, what is the problem?

The problem is that if both of you and your partner have thalassaemia minor, you could have children with thalassaemia major.

What is thalassaemia major?

Thalassaemia major is a condition which causes a severe anaemia.

People who have thalassaemia major are dependent on regular blood transfusions and need daily drug therapy. Without treatment, these people die from the effects of the anaemia within the first few years of life.

Is thalassaemia more common in some ethnic groups than others?

Thalassaemia may occur in people of any origin, however it is more common in people from Mediterranean countries such as Cyprus, Greece, Italy, Turkey, Malta and Egypt, and is also common in people from the Middle-East, Indian sub-continent, South-East Asia and Southern China.

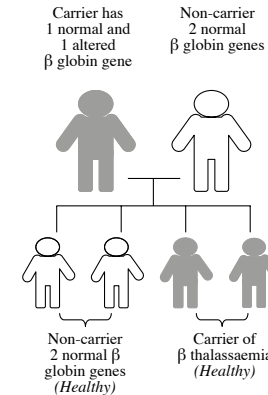
In Australia, thalassaemia minor is common.

Why is thalassaemia more common in these ethnic groups?

The reason is not completely clear, but thalassaemia may have had some protective effect against malaria, which was also common in these countries.

Will my children be affected?

How children may be affected is dependent on whether one or both partners have thalassaemia minor.



(a) If only one partner has thalassaemia minor

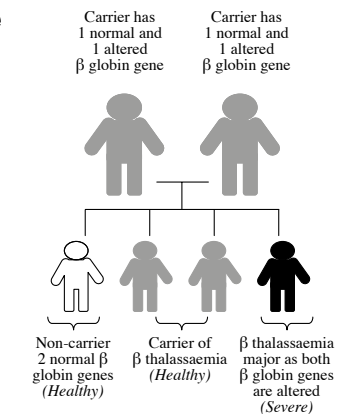
In each pregnancy there is a 50% chance that you will have a child with thalassaemia minor and a 50% chance that you will have a child with no thalassaemia.

There is no risk that you will have a child with thalassaemia major.

(b) If both parents have thalassaemia minor

In each pregnancy there is a 25% chance that your child will have thalassaemia major.

There is also a 25% chance the child will not have thalassaemia and a 50% chance that the child will have thalassaemia minor.



If both parents have thalassaemia minor and are planning to have children, there are several options open to you and it is important that you discuss these with the relevant health professionals.