

Information for you

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Beta thalassaemia and pregnancy

About this information

This information is for you or if you have beta thalassaemia major or intermedia and would like to know more about what this means in pregnancy. It may also be helpful for partners, relatives or friends of someone who has beta thalassaemia and therefore the condition is explained below first.

What are the thalassaemias?

Thalassaemias are conditions that affect the red blood cells and the haemoglobin they contain. Haemoglobin is the protein that carries oxygen around the body. It is produced in the bone marrow (a spongy material found inside bones) using iron that we get from our diet.

Haemoglobin is made of two matching pairs of proteins (chains). To work properly, it needs two alpha chains and two beta chains. For someone with beta thalassaemia, one or more of the beta protein chains are not made properly and the bone marrow cannot produce enough haemoglobin. This leads to anaemia and the blood cells being less able to carry oxygen.

What causes beta thalassaemia?

You cannot catch beta thalassaemia. It is caused by a change in the gene that makes haemoglobin. It is an inherited condition, which means that it is passed down through families:

- If someone has two of these genes (one from each parent), they will either have the serious condition beta thalassaemia major or, if symptoms are less severe, beta thalassaemia intermedia.
- If someone has only one of these genes (from one parent), they will be a carrier of the condition.

It is one of the most commonly inherited conditions in the world. It mostly affects people whose family origins are in the Mediterranean, India, Pakistan and Bangladesh.

About 1000 people in the UK have beta thalassaemia major or intermedia.



What does having beta thalassaemia mean?

- **Beta thalassaemia major:** People with beta thalassaemia major will need regular blood transfusions all their life. It can lead to too much iron in their body (iron overload), which can cause problems with organs such as the liver, heart, lungs, pancreas and pituitary gland. To prevent this happening, medication is needed to reduce the iron in their body. This is called iron chelation and is usually given by injection.
- **Beta thalassaemia intermedia:** The effects of beta thalassaemia intermedia can vary. Some people know they have it from childhood. Others only find out later in life when they are diagnosed with anaemia.

I have beta thalassaemia. What should I think about before becoming pregnant?

If you have beta thalassaemia major or intermedia, it is important to let your medical team know that you are planning to have a baby. They will be able to help you to be in the best possible health before you become pregnant.

If your iron load is high, your medical team may recommend that you have iron chelation before you get pregnant. This is because iron chelation is best avoided in the early stages of pregnancy as it might affect your baby's development.

Sometimes having beta thalassaemia means that you might find it harder to get pregnant. You can be referred to a fertility specialist to discuss your options. If your periods are not regular, bringing down your iron levels may help.

What extra tests should I have before I get pregnant?

- You should see a heart specialist who will arrange tests to check that your heart is working normally. Pregnancy places an extra strain on the heart so it is important that the medical team knows as much as possible about your heart before you get pregnant.
- You should also have your liver checked by a scan and a blood test to make sure that there is no evidence of iron overload and to check for hepatitis B and C.
- If you have diabetes, you should be referred to a diabetes specialist. It is essential that you control your blood sugar before pregnancy. If you have not previously been diagnosed with diabetes, you should be tested for this before getting pregnant.
- An underactive thyroid gland is common with thalassaemia. You should have a blood test to check that it is working properly.
- You should be offered a bone density scan if you are planning to have a baby because osteoporosis is common with thalassaemia.
- You should have your blood checked for blood group antibodies that could affect you or your baby. This is a routine test offered to all pregnant women, but the risk of having these antibodies is greater if you have had blood transfusions in the past.

What extra treatment might I need?

You should start taking folic acid at least three months before getting pregnant. You will need 5 mg daily. This is a higher dose than the usual dose recommended for all women planning a pregnancy.

Like all pregnant women, you should also take vitamin D. Talk to your medical team about the right dose for you.

Your vaccination for hepatitis B should be up to date.

If you have had your spleen removed, you will be advised to take penicillin (or an alternative if you are allergic to penicillin) to prevent infection. You may also be advised to have additional vaccinations.

Can I pass the beta thalassaemia gene on to my baby?

Yes. Your baby will inherit one gene from you and one from the baby's father. If you have beta thalassaemia major or intermedia, you will pass the affected gene on to your baby.

Whether your baby has beta thalassaemia major depends on whether the baby's father also has thalassaemia. Therefore, it is very important that you consider finding out whether your partner is also affected *before* getting pregnant.

- If your partner does not carry any type of thalassaemia, your baby will be a healthy carrier of beta thalassaemia.
- If your partner has beta thalassaemia major or intermedia, or is a carrier, there is a chance that your baby will have beta thalassaemia major. Specialist counselling is available. This will help you both decide whether to have tests when you become pregnant to find out if your baby has the condition. This can be a difficult decision for many couples and further information is available from the NHS Sickle Cell and Thalassaemia Screening Programme at: <http://sct.screening.nhs.uk> and <http://sct.screening.nhs.uk/professional-leaflets>.

What are the risks to me and my baby in pregnancy and what extra care will I receive?

You will receive antenatal care from a specialist team of obstetricians, midwives, haematologists (blood specialists), cardiologists (heart specialists) and nurse specialists.

- If you are already having regular blood transfusions, you are likely to continue to need these during pregnancy. If you are not having blood transfusions, your blood count will be monitored: you might need a transfusion if you become anaemic, if you develop symptoms and/or if your baby's growth is affected. If your medical team is concerned about iron overload, you may be advised to have iron chelation after 20 weeks of pregnancy to reduce your iron levels.
- Your heart and liver will be checked regularly.
- You are at increased risk of developing diabetes during pregnancy. This is known as gestational diabetes. You should be tested for this at between 24 and 28 weeks. If the test confirms the diagnosis, you will be referred to a specialist team. You can find out more about this from the RCOG patient information *Gestational diabetes*, which is available at: www.rcog.org.uk/en/patients/patient-leaflets/gestational-diabetes.
- Pregnant women have a higher risk of developing blood clots in their legs (deep vein thrombosis or DVT) compared with women who are not pregnant. Thalassaemia makes you more likely to develop a venous thrombosis. You can find out more about this from the RCOG patient information *Reducing the risk of venous thrombosis in pregnancy and after birth*, which is available at: www.rcog.org.uk/en/patients/patient-leaflets/reducing-the-risk-of-venous-thrombosis-in-pregnancy-and-after-birth).
- If you have had your spleen removed, you may already be taking a low dose (75 mg) of aspirin. You must continue this. If you aren't already on low-dose aspirin, you may be advised to start this during your pregnancy.
- Having thalassaemia can affect the way your baby grows in the womb by causing the placenta not to work as well as it should. This is known as fetal growth restriction. You can find out more

about this from the RCOG patient information *Having a small baby*, which is available at: www.rcog.org.uk/en/patients/patient-leaflets/having-a-small-baby. Your baby's growth will be monitored closely with regular ultrasound scans. If there are concerns about your baby's growth, you may be advised to have your baby earlier than your due date.

What will happen to me in labour and after the birth of my baby?

Unless there are other medical reasons, you should be able to have a normal vaginal birth. You should be looked after in a consultant-led unit with neonatal facilities.

It is unlikely that you will need a blood transfusion around the time of birth but your medical team will have blood available for you.

If you have had blood transfusions during pregnancy, you may be advised to have iron chelation around the time of labour.

You will be recommended to have heparin injections for up to six weeks after your baby is born to reduce the risk of a DVT.

Can I breastfeed my baby?

Yes. It is a good idea to do so. Usually you will be recommended to restart chelation treatment soon after the birth. Make sure your team knows that you are breastfeeding to ensure you receive iron chelation that is safe for your baby.

Key points

- The thalassaemias are among of the most common inherited conditions in the world.
- If you are planning a pregnancy, let your thalassaemia team know so that they can review your medicines and vaccinations and make sure your checks are up to date.
- You and your partner can meet a specialist or counsellor to discuss the chances of beta thalassaemia being passed on to your baby and the tests available for you.
- A specialist team will look after you and your baby very closely during pregnancy.
- Breastfeeding is safe and good for your baby.

Further information and support

NHS Sickle Cell and Thalassaemia Screening Programme: <http://sct.screening.nhs.uk> and <http://sct.screening.nhs.uk/professional-leaflets>

NHS Choices – Thalassaemia: www.nhs.uk/conditions/Thalassaemia/Pages/Introduction.aspx

Making a choice

Shared Decision Making

If you are asked to make a choice, you may have lots of questions that you want to ask. You may also want to talk over your options with your family or friends. It can help to write a list of the questions you want answered and take it to your appointment.



Ask 3 Questions

To begin with, try to make sure you get the answers to three key questions if you are asked to make a choice about your healthcare.

1. What are my options?
2. What are the pros and cons of each option for me?
3. How do I get support to help me make a decision that is right for me?

These resources have been adapted with kind permission from the MAGIC Programme, supported by the Health Foundation

* Ask 3 Questions is based on Shepherd HL, et al. Three questions that patients can ask to improve the quality of information physicians give about treatment options: A cross-over trial. Patient Education and Counselling, 2011;84: 379-85



<http://www.advancingqualityalliance.nhs.uk/SDM/>

Sources and acknowledgements

This information has been developed by the RCOG Patient Information Committee. It is based on the RCOG guideline *Management of Beta Thalassaemia in Pregnancy* (March 2014), which contains a full list of the sources of evidence we have used. You can find it online at: www.rcog.org.uk/en/guidelines-research-services/guidelines/gtg66.

This leaflet was reviewed before publication by women attending clinics in London, Luton, Manchester and Birmingham, and by the RCOG Women's Voices Involvement panel.

The RCOG produces guidelines as an educational aid to good clinical practice. They present recognised methods and techniques of clinical practice, based on published evidence, for consideration by obstetricians and gynaecologists and other relevant health professionals. This means that RCOG guidelines are unlike protocols or guidelines issued by employers, as they are not intended to be prescriptive directions defining a single course of management.

A glossary of all medical terms is available on the RCOG website at: www.rcog.org.uk/womens-health/patient-information/medical-terms-explained.

A final note

The Royal College of Obstetricians and Gynaecologists produces patient information for the public. The ultimate judgement regarding a particular clinical procedure or treatment plan must be made by the doctor or other attendant in the light of the clinical data presented and the diagnostic and treatment options available. Departure from the local prescriptive protocols or guidelines should be fully documented in the patient's case notes at the time the relevant decision is taken.

All RCOG guidelines are subject to review and both minor and major amendments on an ongoing basis. Please always visit www.rcog.org.uk for the most up-to-date version of this guideline.