Thalassaemia in pregnancy

About this information

This inforwhmation is for you if you have thalassaemia and would like to know more about what this means in pregnancy.

It may also be helpful if you are a partner, relative or friend of someone who has thalasaemia.

The information here aims to help you better understand your health and your options for treatment and care. Your healthcare team is there to support you to make decisions that are right for you. They can help by discussing your situation with you and answering your questions.

Within this leaflet we may use the terms ‘woman’ and ‘women’. However, we know that it is not only people who identify as women who may need to access this leaflet for information. Your care should be appropriate, inclusive and sensitive to your needs whatever your gender identity.

A glossary of all medical terms is available on the RCOG website at: https://www.rcog.org.uk/for-the-public/a-z-of-medical-terms/

Key points

- Thalassaemia is one of the most common inherited conditions in the world.
- If you are planning a pregnancy, let your thalassaemia team know so they can review that your medicines and vaccinations are up to date.
- You and your partner can meet a specialist or counsellor to discuss the chances of thalassaemia being passed on to your baby and the tests available to you.
- A specialist team will look after you and your baby very closely during pregnancy.
- Thalassaemia does not affect your choice of how to feed your baby. Breastfeeding is safe.

What is thalassaemia?

Thalassaemia is a group of conditions that affect your red blood cells and the haemoglobin (Hb) they contain. Haemoglobin is the protein that carries oxygen around the body. It is produced in the bone marrow (a 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 thalassaemia, one or more of the 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 thalassaemia?

Thalassaemia is caused by a difference in the genes that make haemoglobin. It is an inherited condition, which means that the affected genes have been passed on from parents to their child. It is not caused by anything that the parents did before or during the pregnancy and you cannot catch thalassaemia.

If someone has only one of these genes (from one parent), they will be a ‘carrier’ of the condition. Carriers do not have thalassaemia but can have a child with thalassaemia if their partner is also a carrier, or has thalassaemia. To have thalassaemia, a child has inherited an affected gene from each of their parents. This is discussed in more detail below in: *Can I pass thalassaemia on to my baby?*

There are different types of thalassaemia, depending on which genes are involved. *Thalassaemia major* is the most severe type. Less severe types include *thalassaemia intermedia* and HbH disease.

Thalassaemia is one of the most commonly inherited conditions in the world. It mostly affects people whose family origins are in the Mediterranean (such as Italy, Greece, Cyprus), India, Pakistan, Bangladesh, the Middle East, China and Southeast Asia. About 2300 people in the UK have thalassaemia, with around 800 having the most severe form.[1]

What does having thalassaemia mean?

- Having thalassaemia leads to anaemia, as the haemoglobin in your blood is not working properly. Anaemia produces symptoms such as severe tiredness, weakness, shortness of breath, palpitations and looking very pale. Some people may have other effects such as delayed growth, weak bones (osteoporosis), and reduced fertility.
- **Beta thalassaemia major:** People with beta thalassaemia major will need regular blood transfusions all their life to treat their anaemia. This 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.
- **Thalassaemia intermedia:** The effects of less severe forms of thalassaemia 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 thalassaemia. What should I think about before becoming pregnant?

If you have thalassaemia, it is important to tell your specialist thalassaemia team/hematologist that you are planning to have a baby. They will be able to help you to be in the best possible health before you try to become pregnant.

Sometimes having 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 level may help.

What extra tests should I have before I get pregnant?

Before you get pregnant, your team should offer you:

- 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.
- A liver scan and a blood test to make sure there is no evidence of iron overload and to check for hepatitis B and C.
- A blood test for diabetes. If you have diabetes already, it is very important that your blood sugar is well controlled before pregnancy. You may need referral to a diabetes specialist.
- A blood test to check your thyroid levels. An underactive thyroid gland is common with thalassaemia.
- A bone density scan because osteoporosis is common with thalassaemia.
- A blood test for blood group antibodies. 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 before pregnancy?

Folic acid: You should start taking folic acid at least three months before getting pregnant. You will need 5 mg daily, which needs to be prescribed by a healthcare professional. This is a higher dose than the usual dose recommended to help your body make more haemoglobin.

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

Vaccination: Your vaccination for hepatitis B should be up to date.

Iron load: 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.

Infection prevention: 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 thalassaemia on to my baby?

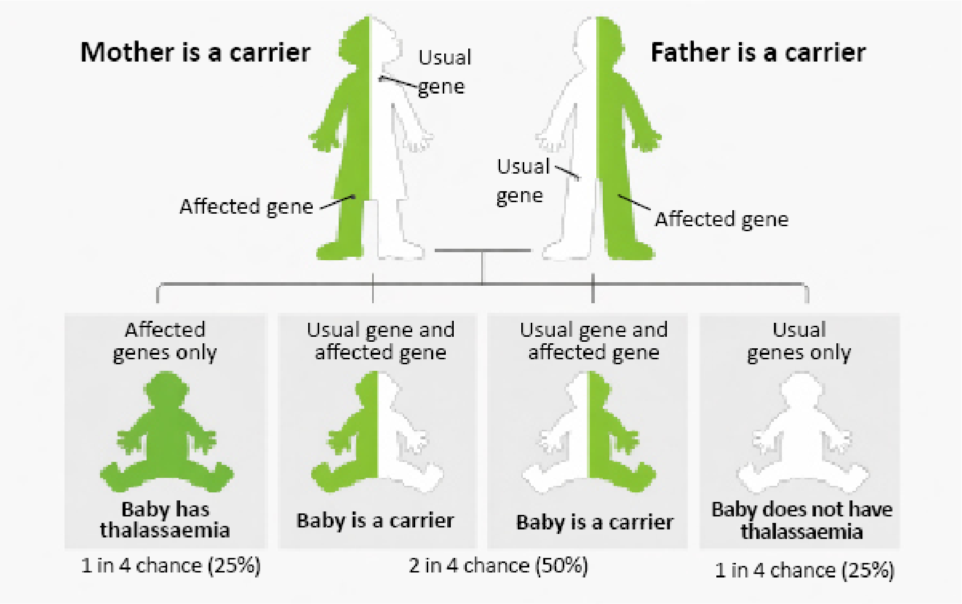
Yes. Your baby will inherit one hemoglobin gene from you and one from the baby's father. If you have thalassaemia, the affected gene will be passed on to your baby. Whether your baby has thalassaemia depends on whether the baby's father also has thalassaemia, or is a carrier. Therefore, it is very important your partner considers being tested before trying to get pregnant.

- If your partner does not have any type of thalassaemia, your baby will be a healthy carrier of thalassaemia (see diagram below).

- If your partner has thalassaemia, or is a carrier, there is a chance that your baby will have thalassaemia. You should be referred for specialist genetic counselling to discuss your options before becoming pregnant and during pregnancy. The decisions about testing can be difficult for many parents and further information is available from the NHS Sickle Cell and Thalassaemia Screening Programme at: https://www.gov.uk/government/publications/baby-at-risk-of-having-thalassaemia-description-in-brief/information-and-choices-for-women-and-couples-at-risk-of-having-a-child-with-thalassaemia-major

  The above NHS information also provides details on pre-implantation genetic diagnosis (PGD) and assisted pregnancy using donated eggs or sperm from people who are not carriers.

The diagram below shows the chance of a child inheriting thalassaemia if both parents are carriers of the affected gene:



What extra care will I receive in pregnancy to keep me and my baby safe?

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 haemoglobin level 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 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.

- Pregnant women have a higher risk of developing blood clots in their legs or lungs (deep vein thrombosis or DVT or pulmonary embolism) compared with women who are not pregnant. Thalassaemia makes you more likely to develop thrombosis. You may be offered preventative treatment with heparin injections, depending on any other risk factors. You can find out more about this from the RCOG patient information Reducing the risk of venous thrombosis in pregnancy and after birth.
- If you have had your spleen removed, you may already be taking low-dose aspirin. You must continue this. If you aren't already on a low dose of aspirin, you will be advised to start this from 12 weeks of your pregnancy to reduce the risk of developing pre-eclampsia.
- 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. 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 are the options for the birth of my baby?

Your specialist team will be able to discuss your choices with you. Unless there are other medical reasons, you can choose to have a vaginal birth. You will be offered continuous monitoring of your baby's heart rate during labour.
You should be looked after in a consultant-led unit with neonatal facilities available in case your baby needs extra care after birth.

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 your baby's birth.

You may be recommended to have heparin injections for up to six weeks after your baby is born to reduce the risk of thrombosis, depending on your individual situation.

Can I breastfeed my baby?

Yes. Thalassaemia does not affect your choice of how to feed your baby. If you were on chelation treatment before pregnancy, usually it is recommended to restart this soon after birth. Make sure your team knows that you are breastfeeding to ensure you receive iron chelation that is safe for your baby.

Emotional support

Having thalassaemia in pregnancy can be distressing. If you are feeling anxious or worried in any way, please speak to your healthcare team who can answer your questions and help you get support. The support may come from healthcare professionals, voluntary organisations or other services. Further information and resources are available on the NHS website:

https://www.nhs.uk/conditions/stress-anxiety-depression/

Further information and support

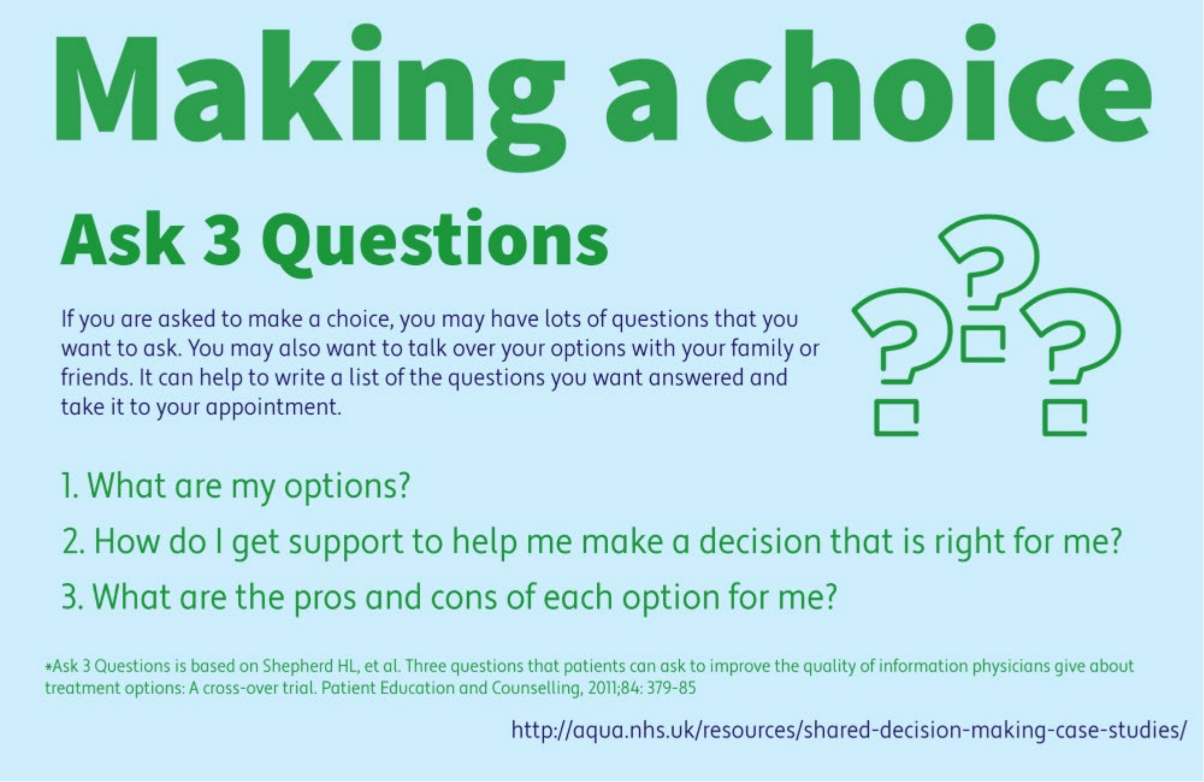
NHS Sickle Cell and Thalassaemia Screening Programme:
https://www.gov.uk/guidance/sickle-cell-and-thalassaemia-screening-programme-overview

NHS Choices – Thalassaemia:
https://www.nhs.uk/conditions/thalassaemia

nhs.uk/conditions/thalassaemia/treatment

United Kingdom Thalassaemia Society
ukts.org/

Making a Choice



Making a choice

Ask 3 Questions

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.

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

*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://aqua.nhs.uk/resources/shared-decision-making-case-studies/

Sources and acknowledgements

This information has been developed by the RCOG Patient Information Committee. It is based on the British Society for Haematology guideline [Guideline for the Management of Conception and Pregnancy in Thalassaemia Syndromes,] which contains a full list of the sources of evidence we have used.

1. https://www.england.nhs.uk/2024/08/gene-editing-therapy-that-could-cure-blood-disorder-thalassaemia-for-nhs-patients/