



Information for you

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Molar pregnancy and gestational trophoblastic disease

About this information

This information is for you if you have been diagnosed with molar pregnancy or another type of gestational trophoblastic disease (GTD). Molar pregnancy is one of a number of different conditions that are called gestational trophoblastic disease (GTD). These rare conditions happen when a pregnancy does not develop normally from the very beginning.

This information may also be helpful if you are a partner, relative or friend of someone in this situation.

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 in making decisions that are right for you. They can help by discussing your situation with you and answering your questions.

A glossary of medical terms is available on the RCOG website at: www.rcog.org.uk/en/patients/medical-terms.

Key points

- GTD is an **uncommon** group of conditions that includes complete and partial molar pregnancies.
- Molar pregnancy is an abnormal form of pregnancy that cannot develop into a healthy baby.
- Treatment of a molar pregnancy is usually a small operation to remove abnormal pregnancy tissue from your uterus (womb).
- Uncommonly molar pregnancy tissue can persist after surgery and you might need further treatment with chemotherapy.
- Gestational trophoblastic neoplasia (GTN) is a rare form of cancer which includes invasive molar pregnancy.
- You will be followed up in a specialist centre with expertise in the management of molar pregnancy and GTD.



What is GTD?

GTD is an uncommon group of conditions that happen when a pregnancy does not develop normally from the very beginning. GTD includes complete molar pregnancy, partial molar pregnancy and other much rarer conditions. For every 714 pregnancies which end with a live baby, there will be one pregnancy which develops GTD.

What is a molar pregnancy?

Molar pregnancy (also called hydatidiform mole) is the most common type of GTD. In healthy pregnancies a **fetus** develops when one sperm fertilises one egg and chromosomes from each combine. The baby will have two sets of **chromosomes** – one from each parent. A molar pregnancy is abnormal from the very moment of **conception** because of an imbalance in the number of chromosomes supplied from the mother and the father. Molar pregnancies cannot develop into a healthy baby. There is nothing you can do to reduce your chance of developing a molar pregnancy.

There are two types of molar pregnancy:

Complete molar pregnancy

- This usually happens when a single sperm fertilises an 'empty' egg which has no genetic material inside. The sperm's chromosomes double up to give the fertilised egg two sets of chromosomes which have both come from the father.
- Complete moles can also occur when two sperm fertilise an 'empty' egg.
- There is no sign of a developing fetus in a complete molar pregnancy.

Partial molar pregnancy

- This usually happens when two sperm fertilise a normal egg meaning the developing pregnancy has three sets of chromosomes, two from the father and one from the mother. In a partial mole, there are usually some early signs of development of a fetus, but this is always abnormal and cannot survive.

Rarely, a molar pregnancy may develop in one of a set of twins. If you are suspected to have this rare type of pregnancy you should be referred to a specialist centre which has experience of this.

When might a molar pregnancy be suspected?

If you have a molar pregnancy it is common to experience irregular or heavy vaginal bleeding in early pregnancy.

You should be referred to an **early pregnancy assessment unit** for a transvaginal (internal) ultrasound scan. Molar pregnancy may show up on an ultrasound scan but sometimes the scan only shows what looks like a miscarriage or an empty pregnancy sac. Molar pregnancy can be difficult to diagnose. If there is any doubt you will be offered further scans and investigations.

The levels of the pregnancy hormone **hCG (human chorionic gonadotrophin)** in your blood are much higher in a molar pregnancy than in a healthy pregnancy. You may be offered a blood test to check for this.

Sometimes a molar pregnancy is only found when pregnancy tissue is sent to the laboratory (lab) after a miscarriage. Examining pregnancy tissue in the lab is the only way to confirm the diagnosis of molar pregnancy.

What happens if a molar pregnancy is suspected?

The best treatment for a molar pregnancy is an operation to remove the pregnancy tissue from your uterus as this is not a healthy pregnancy. This operation is usually done under general anaesthetic and

involves a small suction tube being passed through your vagina and your cervix (the neck of your womb) to remove the abnormal pregnancy tissue. This tissue will be sent to the lab to confirm the diagnosis of molar pregnancy.

Why do I need to be sure if I have had a molar pregnancy?

It is important to be sure if you have had a molar pregnancy as there is a small risk that some of the abnormal pregnancy cells may develop into a more severe form of GTD (see below). This may mean that you need further treatment.

What follow-up will I have?

In the UK all women who have had a molar pregnancy are asked if their details can be registered with a specialist centre so that treatment can be coordinated and provided by experts in this field. These centres are at hospitals in London, Sheffield and Dundee (see contacts below).

Follow-up involves measuring the pregnancy hormone hCG, either in your blood or your urine, until it returns to normal. The specialist centre will post you the kit that you need and you will have your blood tests done at your GP surgery or local hospital. If you are asked to give a urine specimen, written information will be given on how to do this. If the level of hCG is falling in your blood or urine, it means the number of abnormal cells in the uterus is also falling and you probably won't need any more treatment.

How long you receive follow-up will depend on your individual situation and whether you have had a partial or a complete molar pregnancy. Partial molar pregnancies are followed up until your hCG level is normal on two samples taken 4 weeks apart. Complete molar pregnancies are followed up for at least 6 months from the date you had your surgery, and for longer if your hCG levels are falling more slowly.

Continuing with this specialist follow-up is important as it is very successful in treating GTD (98–100% cure rate) and there are very low rates of progression to more serious forms of GTD.

What is GTN?

Gestational trophoblastic neoplasia (GTN) is a rare form of cancer. A molar pregnancy can be thought of as a precancerous illness which can occasionally progress to GTN.

GTN usually happens when molar pregnancy cells keep growing in your uterus. It is usually diagnosed when your hCG level does not return to normal during follow-up.

GTN can also happen after a miscarriage or the birth of a baby. This is much rarer than after a molar pregnancy, happening only once in every 50 000 babies born.

GTN has an overall cure rate of close to 100%.

What happens if I have GTN?

If you are diagnosed with GTN, you will usually need to have further treatment. This will be organised by the specialist centre that you have been registered with.

Further treatment usually involves drugs (chemotherapy), although sometimes you may be offered a second operation to empty your uterus. Around 1 in 7 women who have had a complete mole and 1–2 in 200 women who have had a partial mole will need chemotherapy. This is usually straightforward with few side effects.

The number and type of drugs used will depend on your age, the type of pregnancy you have had, your blood hCG levels before treatment and how long it has been since your pregnancy ended.

Treatment is continued until 6 weeks after your hCG level has returned to normal.

Surgery, such as hysterectomy (removal of your uterus), may be recommended if you have one of the much less common types of GTN.

When can I get pregnant again?

Having a molar pregnancy does not affect your chance of having another baby. However, after a molar pregnancy you should avoid pregnancy until your follow-up programme is complete.

If you have chemotherapy for GTN, your periods will usually stop during treatment. They nearly always restart within a few weeks to months after completing chemotherapy and over 80% of women who have had chemotherapy for GTN will have another pregnancy. If you needed high dose chemotherapy, your fertility may not return after treatment. The need for high dose chemotherapy is very rare.

If you have had chemotherapy for GTN, you are advised not to get pregnant for 12 months after your treatment is complete.

Are there any long-term problems after treatment for GTN?

There is a chance your menopause may happen earlier than it would have normally, especially if you have needed more than one chemotherapy drug for treatment. It is safe to use **HRT** (hormone replacement therapy) if needed once your hCG level has returned to normal.

What contraception can I use during follow-up?

Most methods of contraception are safe to use after treatment for GTD. They can be started straight after the pregnancy tissue has been removed. You should not have an intrauterine contraceptive device (a copper coil [IUD] or hormone coil [IUS]) fitted until your hCG level has returned to normal as it is more likely to cause a perforation in the uterus if it is put in too soon after treatment for a molar pregnancy.

Your healthcare professional should discuss your options for contraception with you and answer any questions you may have.

Will I have another molar pregnancy?

The risk of a molar pregnancy happening again is low. For 99 out of 100 women their next pregnancy will not be a molar pregnancy.

Support after a molar pregnancy, GTD or GTN

Being diagnosed with GTD or GTN can be a frightening experience which may affect you physically and emotionally. You should be offered information and support about your diagnosis and throughout your treatment. There are specialist healthcare professionals available to support you at the central GTD centres and online support groups are available.

About intimate examinations

The nature of gynaecological and obstetric care means that intimate examinations are often necessary.

We understand that for some people, particularly those who may have anxiety or who have experienced trauma, physical or sexual abuse, such examinations can be very difficult.

If you feel uncomfortable, anxious or distressed at any time before, during, or after an examination, please let your healthcare professionals know.

If you find this difficult to talk about, you may communicate your feelings in writing.

Your healthcare professionals are there to help and they can offer alternative options and support for you.

Remember that you can always ask them to stop at any time and that you are entitled to ask for a chaperone to be present. You can also bring a friend or relative if you wish.

Further information

National screening centres:

Sheffield Trophoblastic Disease Centre

Weston Park Hospital

Whitham Road

Sheffield S10 2SJ

Tel: +44 114 226 5205

Email: sht-tr.trophoblastic@nhs.net

Website: www.chorio.group.shef.ac.uk/index.html

Charing Cross Trophoblastic Disease Service

Department of Medical Oncology

Charing Cross Hospital

Fulham Palace Road

London W6 8RF

Tel: +44 (20) 3311 1409

Email: hmole-chorio@imperial.nhs.uk

Website: www.hmole-chorio.org.uk

Scottish Hydatidiform Mole Service

NHS Tayside

Ninewells Hospital and Medical School

Dundee DD1 9SY

Tel: +44 1382 632748

Email: hmolescotland.tayside@nhs.net

Website: www.nss.nhs.scot/specialist-healthcare/specialist-services/hydatidiform-mole/

Molar Pregnancy – Support & Information: molarpregnancy.co.uk

RCOG patient information:

- Understanding how risk is discussed in healthcare (<https://www.rcog.org.uk/en/patients/patient-leaflets/understanding-how-risk-is-discussed-in-healthcare>)
- Early miscarriage (www.rcog.org.uk/en/patients/patient-leaflets/early-miscarriage)
- Recovering from surgical management of a miscarriage (www.rcog.org.uk/en/patients/patient-leaflets/recovering-from-surgical-management-of-a-miscarriage)

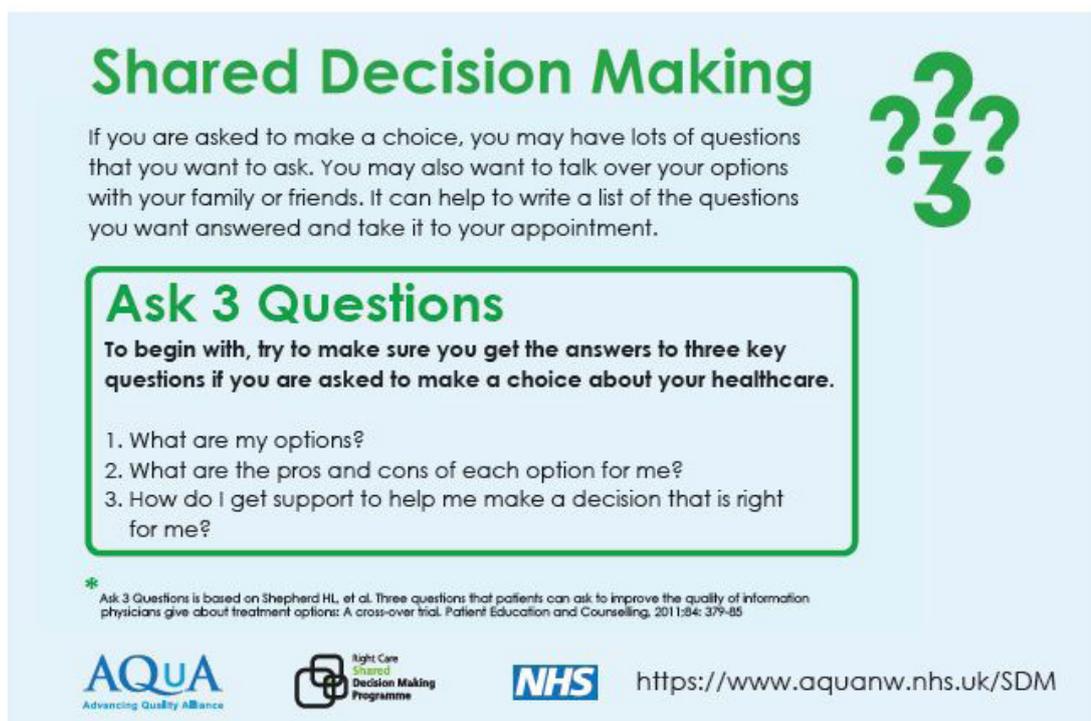
Miscarriage Association: www.miscarriageassociation.org.uk

Faculty of Sexual and Reproductive Healthcare Guideline Contraception After Pregnancy: www.fsrh.org/news/new-fsrh-guideline--contraception-after-pregnancy

Further information and resources for emotional support are available on the NHS website: www.nhs.uk/conditions/stress-anxiety-depression/

A full list of useful organisations is available on the RCOG website at: www.rcog.org.uk/en/patients/other-sources-of-help

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?

* 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

AQUA Advancing Quality Alliance  **NHS** <https://www.aquanw.nhs.uk/SDM>

Sources and acknowledgements

This information has been developed by the RCOG Patient Information Committee. It is based on the RCOG Green-top Guideline No. 38 Management of Gestational Trophoblastic Disease (Published September 2020). The guideline 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/gtg38.

Before publication this information was reviewed by the public, by the RCOG Women's Network and by the RCOG Women's Voices Involvement Panel.