HYDATIDIFORM MOLE

the women's
the royal women's hospital
victoria australia

This information is for patients who have been diagnosed with a molar pregnancy. This condition may also be called a *hydatidiform mole* or *gestational trophoblastic tumour*.

A molar pregnancy is very uncommon affecting around 1 in 1,200 pregnancies. It is sometimes detected when you have an early pregnancy ultrasound. It may also be diagnosed after a miscarriage, when the tissue that is collected or passed from the uterus is examined. As the condition is unusual and not well known in the community, it can come as a shock, especially if you are still pregnant and coming to terms with the fact that the pregnancy is ending. We hope that the following information will answer most of your questions.

What is a molar pregnancy?

To understand a molar pregnancy you will first need to understand how a normal fertilised egg divides to create the placenta and the fetus.

A normal pregnancy

The woman's egg and the man's sperm meet in a fallopian tube and the egg is fertilised. Over the next few days the fertilised egg moves into the uterus where it attaches to the inner wall. In a normal pregnancy, the outer part of the fertilised egg forms the placenta (after birth), which has many functions, including feeding the fetus and removing waste products. The inner part of the egg develops into a fetus. The placenta produces a pregnancy hormone called human chorionic gonadotrophins (hCG), which supports the ongoing survival of the pregnancy, it also causes symptoms such as morning sickness, tender breasts and lack of energy.

A molar pregnancy

In a molar pregnancy, there is unusual and rapid growth of part or all of the placenta. The placenta becomes larger than normal and contains a number of cysts (sacs of fluid).

In a **complete molar pregnancy**, the growth stops a fetus from developing. In a **partial molar pregnancy**, a fetus develops but it will be abnormal and cannot survive. At most, the fetus might survive for around three months.

In a molar pregnancy, you will have all the usual signs of pregnancy (like morning sickness or sore breasts) because the placenta continues to make the pregnancy hormone hCG. In fact, the placenta often makes higher amounts of this hormone than it would normally.

Most of the time, a molar pregnancy is discovered in the first three months of pregnancy, often because it ends in a miscarriage.

Related problems

In some cases the placenta can become malignant and a rare – but curable – form of cancer, called choriocarcinoma, will develop. Choriocarcinoma can actually develop from a normal pregnancy or miscarriage as well as from molar pregnancy and can spread throughout the body, usually to organs like the lungs, liver and brain. This type of cancer responds very well to chemotherapy.

Why is it called a Hydatidiform mole?

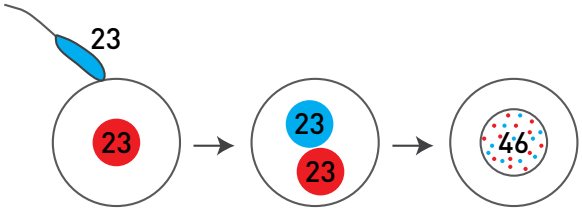
The first part of the name comes from the Greek word "hydatid" meaning droplet. These structures appear to burrow into the wall of the uterus, hence the name mole. The term seems strange but is similar to that used for a harmless growth on the skin, which is also called a mole.

Why did I develop a molar pregnancy?

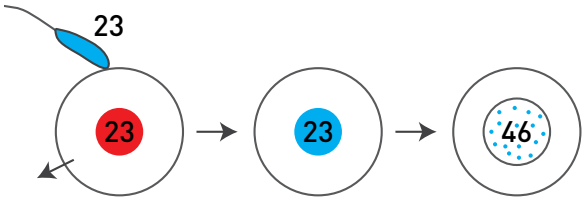
A molar pregnancy occurs when an abnormal egg or sperm join. We don't know why a particular woman has a molar pregnancy, but affected women have been shown to have certain things in common. These are called risk factors and they are:

- age – younger than 20 or older than 40
- Asian background
- nutrition deficiency
- a previous molar pregnancy or other gestational trophoblastic tumour (one in 100 women who have had one molar pregnancy will have another).

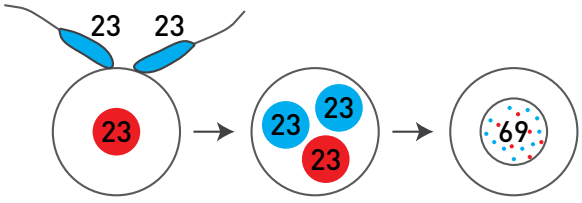
Genetic status in normal conception and molar pregnancy



Normal conception, viable fetus
2 sets of genes, 1 paternal gene, 1 maternal gene



Complete mole, no fetus
2 sets of paternal genes, no maternal genes



Partial mole, non-viable fetus
3 sets of genes, 1 maternal gene, 2 paternal genes

Gestational Trophoblastic Disease (GTD) Registry?

Registries are set up to monitor and to coordinate the follow-up of women who have had a molar pregnancy. The GTD Registry at the Royal Women's Hospital is the only registry in Victoria. There is also a registry in Queensland. After you have been diagnosed, it is very important that your doctor registers your details with us so that we can monitor you and take care of you in the best possible way. The GTD Registry is supported by a team made up of clerical staff, doctors, nurses and psychologists. **If you do not wish your details to be included on the registry please contact the GTD Registry on (03) 8345 2620**.

Why do I need to be monitored?

A molar pregnancy is usually harmless and the only treatment required is removal of the molar tissue from the womb. By monitoring the pregnancy hormone hCG we can detect if there are any remaining molar cells in your body. In about ten per cent of cases the remaining molar cells can keep growing and, if left untreated, can bury into the organs around them. This includes the uterus and rarely, via the blood, other distant organs including the lungs, liver or brain. With regular monitoring we can detect if and when you need to have treatment.

How does the testing work?

You will receive bottles and information so that you can do a 24 hour urine collection. Sometimes you may also need to have a blood test to check the hCG hormone level in the blood. In the week following the collection, you will receive a letter from the Registry about the result and next steps in your follow-up.

For how long will I need to provide samples?

If you are diagnosed with a **partial mole**, your hCG levels will be monitored until the level becomes normal.

In case of a **complete mole**, if your hormone level is normal after two months, follow-up will continue for a further four months with monthly tests.

If it takes longer than two months for your hCG level to become normal, follow-up will be monthly for six months after your hCG level is normal.

The registry will advise you if a different follow-up is required, depending on your individual circumstances.

What if my levels do not fall?

In 10 per cent of cases, the hormone levels do not decrease to normal. This is called **persistent trophoblastic disease**. Tests will give more information about the source of the high hCG levels and include blood tests, a chest X-ray or CT scan and ultrasound. Depending on the outcome of these tests, you will receive the most appropriate therapy.

If you need treatment you will be given further information. You are slightly more likely to need ongoing treatment if you had a complete hydatidiform mole. All women with choriocarcinoma require treatment from the beginning. Treatment is usually chemotherapy given by injection into a muscle or through a drip.

When can I get pregnant again?

It is important for you to avoid getting pregnant again until you are discharged from the GTD Registry. The reason for this is that a new pregnancy will also raise your hCG level and it will not be clear whether this is due to the pregnancy or persistent trophoblastic disease. Once you are discharged from the GTD Registry it is safe for you to attempt a new pregnancy, although we do advise that you wait until you have at least one normal period and more importantly that you are ready emotionally and psychologically.

What contraception should I use?

You may use any contraception you are comfortable with.

What are the chances of a molar pregnancy in the future?

There is a one in 100 or 1 per cent chance that you will develop another molar pregnancy. When you think you are pregnant, let your doctor know so that an early ultrasound can be arranged. Six weeks after the delivery of your baby we recommend that you have one more test to make sure that your hCG level has dropped and that you have not developed further molar disease, which is very rare.

Emotions and support

The end of a wanted pregnancy can be devastating and a molar pregnancy and the possibility of persistent disease adds another layer of concern. For many women, the emotional healing can take longer than the physical healing from treatment. Grief is individual and can affect you and your partner differently. Grief is often poorly understood by friends and family who may not comprehend the complexity of your feelings towards your pregnancy and the reason it ended. Give yourself time to grieve. Talk about your feelings with supportive family and friends. Support from the medical team at the Registry is also available.

Remember

If you do not wish your details to be included on the registry please contact the GTD Registry on (03) 8345 2620.

Further information and support

Gestational Trophoblastic Disease (GTD) Registry

Royal Women's Hospital
T: (03) 8345 2620

The Mole Support Group

A support group has been set up in Victoria for women, partners and others affected by a molar pregnancy. GTD Registry patients will be provided with contact details.

Recommended websites

http://www.molarpregnancy.co.uk
http://www.hmole-chorio.org.uk
http://www.hmole-chorio.org.uk/patients_info.html