## MOLAR PREGNANCY (HYDATIDIFORM MOLE)



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 a very uncommon condition 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, each contributing one set of genes. 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 fertilised 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.

In a normal pregnancy there is a set of genes from the woman and one set of genes from the man.

#### A molar pregnancy

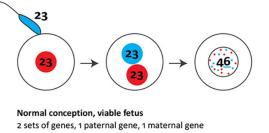
A molar pregnancy occurs when an abnormal egg or sperm join.

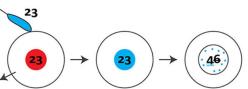
In a **complete molar pregnancy**, there is no fetus. There are two sets of genes from the man.

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. There are two sets of genes from the man and one set of genes from the woman (see picture).

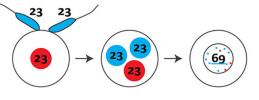
In a molar pregnancy, there is unusual and rapid growth of part or all of the placenta. The placenta becomes larger than normal and contains a number of cysts (sacs of fluid).

#### Genetic status in normal conception and molar pregnancy





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

## Why did I develop a molar pregnancy?

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).

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.

# What is a 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. 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 with surgery known as a curette. 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 spread into the organs around them such as 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 need to have a blood test which can be done at the Women's Pathology on Level 1 or at a pathology service more convenient to you. Sometimes, you may need to submit a 24-hour urine collection. The registry will give you pathology slips and information about the tests required.

In the week following the collection, the Registry will contact you about the next steps in your follow-up.

## 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 for two consecutive tests.

In case of a complete mole follow-up will continue for up to six months after hCG levels return to normal.

The registry will advise you if a different follow-up is required depending on your individual circumstances and the registry doctor's advice.

## What if my levels do not fall?

In ten percent of cases, the hormone levels do not decrease to normal. This is called **persistent trophoblastic disease**. You are slightly more likely to need ongoing treatment if you had a complete molar pregnancy. 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 have an appointment with the registry doctor to discuss this further. Treatment is usually chemotherapy but in a minority of cases there is room to consider surgical options – like a second curette or a hysterectomy (removal of uterus) if you do not wish to have any more children. Your doctor will discuss your treatment options with you.

## 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 1 in 100 (or one percent) 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. Give yourself time to grieve. Try to take it a day at a time and to acknowledge your feelings and reactions as they arise. Talk about your feelings with family and friends.

Sometimes it may be difficult to talk to family and friends, especially if you have chosen not to share the news of your pregnancy. You may prefer to talk with a health professional and support from the Registry is also available. For emotional support or someone to talk to about how you are feeling you can contact the following services at the Women's.

Women's Social Support Services T: (03) 8345 3050 (office hours)

Pastoral Care and Spirituality Services T: (03) 8345 3016 (office hours)

Reproductive Loss Service T: (03) 8345 2498 (office hours)

## For more information

Gestational Trophoblastic Disease (GTD) Registry Royal Women's Hospital T: (03) 8345 2620

#### **Recommended websites**

www.molarpregnancy.co.uk hmole-chorio.org.uk/ www.hmole-chorio.org.uk/patients\_info

#### SANDS (Vic)

Miscarriage, Stillbirth and Newborn Death Support T: (03) 9899 0218

#### **Centre for Grief and Bereavement**

Bereavement Counselling and Support Service T: 1800 642 066 or (03) 9265 2111

#### The Compassionate Friends

T: 1800 641 091 or (03) 9888 4944

#### Related fact sheets on the Women's website Miscarriage

www.thewomens.org.au/health-information/factsheets#miscarriage

#### Remember

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