

Patient Information Leaflet

**MOLAR PREGNANCY**  
( HYDATIDIFORM MOLE).

**Produced By: Early Pregnancy Assessment Unit.**

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## **WHAT IS MOLAR PREGNANCY?**

Molar pregnancy (Hydatidiform mole) is a medical term which means a fluid- filled mass of cells (MOLE = a mass of cells : HYDATID = containing fluid-filled sacs or cysts).

In a molar pregnancy, an abnormal fertilised egg implants in the uterus (womb).

The cells that should become the placenta grow far too quickly and take over the space which the embryo should develop. Those cells are called trophoblasts. That's why molar pregnancy is sometimes called 'trophoblastic disease'.

The hydatidiform mole itself is one of a group of rare conditions called gestational trophoblastic tumours (gestational means pregnancy).

Any mass of cells can be called a tumour. This doesn't mean it is malignant (cancerous): many tumours are benign (harmless).

Approximatley one in 600 pregnancies is a molar pregnancy. This means it is quite rare, especially when compared with miscarriage, which affects approximately one in four pregnancies.

A Hydatidiform mole may be either PARTIAL or COMPLETE depending on the genetic make up of the fertilised egg.

### **Partial mole**

When two sperm fertilise the egg instead of one, creating 69 instead of 46 chromosomes. This is called a 'triploidy'. There is too much genetic material and the pregnancy develops abnormally, the placenta outgrows the baby.

### **Complete mole**

A complete mole is when one or two sperm fertilises an egg cell which has no genetic material inside. Usually the fertilised egg dies at that point but in some rarer cases it goes on to implant in the uterus. When this happens no embryo grows, only the trophoblast ( the cells that will become the placenta) and that grows to fill the uterus with the molar tissue.

## **OTHER COMPLICATIONS**

In a normal pregnancy, the trophoblast invades or burrows into and through the lining of the uterus. However, in approx 14% of complete moles and 1% of partial moles the trophoblast not only grows very quickly, but also burrows more deeply into the uterus than it should.

In these rare cases, the trophoblast cells can become malignant (cancerous) and invade and spread to other parts of the body. This is called 'invasive mole'. If it is not treated it can develop into choriocarcinoma.

### **Choriocarcinoma**

This is an extremely rare complication of hydatidiform mole. Choriocarcinoma more often arises from other types of pregnancy and it affects one in 50,000 pregnancies.

The very small risk of developing invasive mole or choriocarcinoma is the reason that molar pregnancies are followed up. It is also the reason that patients with this condition are followed up at a specialist centre. They are able to detect trophoblastic disease very early and the cure rate is almost 100%.

## **SIGNS AND SYMPTOMS OF MOLAR PREGNANCY**

Some women have no noticeable symptoms of molar pregnancy, or may recognise them only after they have been diagnosed.

This is because most of the symptoms are due to very high levels of the pregnancy hormone hCG (human chorionic gonadotrophin), so the symptoms can be very similar to normal pregnancy or miscarriage.

The sign and symptoms are mainly:

- Missed period/s and a strong positive pregnancy test.
- A lot of nausea (feeling sick) or vomiting. This can be very troublesome.
- Irregular bleeding from the vagina. The blood may contain little fluid filled cysts (like tiny grapes).
- Symptoms similar to miscarriage, including pain and bleeding.

### **Diagnosing molar pregnancy**

After a miscarriage

Most cases of molar pregnancy are diagnosed after what appeared to be a 'normal' miscarriage when a surgical procedure is carried out. This is known as an ERPC (evacuation of retained products of conception)

A sample of tissue that has been removed is sent to the hospital laboratory, where it will be examined. This examination can identify molar tissue and therefore a molar pregnancy.

There may be a delay following your ERPC and when you are told that you may have a molar pregnancy. It may be a few weeks after your miscarriage when you are contacted by letter or telephone. You will be asked to return to see a doctor before you are told any more.

During pregnancy

In some cases, a GP or hospital doctor might suspect a molar pregnancy. If so, you will be referred for the following;

- A blood test which will measure your pregnancy hormone level (hCG). This may be repeated after a few days if the first result is inconclusive.
- An ultrasound scan usually arranged by the Early Pregnancy Assessment Unit.

If your doctor diagnoses or strongly suspects a molar pregnancy they will recommend that you have an ERPC to remove the pregnancy tissue. The diagnosis will then be confirmed by the hospital laboratory.

It is VERY important that you understand that this process is NOT a termination of pregnancy. In most cases an embryo had not formed or it had died at a much earlier stage. Even so, you may feel a sense of loss for your baby, which is a normal emotion to feel at this time.

### **What happens next?**

All women who are diagnosed with molar pregnancy are followed up for at least 6 months to check that their hCG levels have returned to normal.

The hCG levels are tested on samples of blood (serum) and/or urine. The results are reported as IU/L,

which means International Units of hCG per Litre. The normal serum level is 4 IU/L or less and the normal urine level is 24 IU/L or less.

- In most women, the hCG levels drop fairly quickly. If the level of serum hCG drops to normal within eight weeks, you will then be followed up for a total of six months from the date of your ERPC.
- You will be advised not to get pregnant in this time.

If your hCG level;

- doesn't return back to normal
- stays the same for three successive samples or
- starts to rise again

your doctor will then recommend further treatment.

Approximately one in ten women need additional drug treatment (chemotherapy) which will destroy any remaining molar cells.

This treatment is very effective and will not normally affect your chances of having a successful pregnancy in the future.

### **Who carries out the follow up procedure?**

There are three specialist centres in the UK, our patients are referred to Charing Cross Hospital in London.

You are unlikely to have to go there yourself, as they will arrange for your local hospital or clinic to take blood samples and to send them on.

They will send your test results to your GP and your hospital consultant, but you can also contact them directly and they will tell you how you are doing.

### **What if I have an invasive mole or develop choriocarcinoma?**

The chances of you having an invasive mole or developing choriocarcinoma are really very small. But if you have either, the staff at your follow up centre will give you clear advice and guidance.

You will be informed if you need any further investigations, such as ultrasounds, X-ray, CT or MRI scans.

Drug treatment is very effective. Once this has been completed successfully, you will be advised to wait one year before trying for another pregnancy.

There is no increased risk of having an abnormal baby because of chemotherapy.

### **How can I help myself ?**

- Always send the samples on the date requested - please don't delay.
- It is very important that you don't get pregnant whilst you are still being followed up. Pregnancy produces hCG, so it will be very difficult to know whether increasing hCG levels are from the new pregnancy or from molar tissue growing again.
- If you do happen to get pregnant again it is very important to inform the follow up service.
- Condoms used with spermicidal pessaries, cream or jelly are the only contraceptives

recommended during this time and they can be obtained free of charge from your GP or local Family Planning Clinic.

## **Frequently asked questions**

### ***Do I have Cancer?***

If you have a hydatidiform mole that has not needed to be treated with chemotherapy, then you do **not** have cancer. A very small proportion of molar pregnancies can develop into an invasive mole or choriocarcinoma, which is a form of cancer. Fortunately it is a cancer with an almost 100% cure rate.

### ***I feel different having had a hydatidiform mole. Is this normal?***

This is a common feeling. Trophoblastic tissue is found in all pregnancies and is normal. A mole is different only because the growth of the trophoblast was not "switched off" at the right time. It was a pregnancy which did not have a baby to control it.

### ***Was I ever pregnant? Should I be grieving?***

You had the beginnings of a pregnancy which, sadly could never develop or survive. Many women feel a real sense of loss for the baby that might have been. Others prefer to think of it as not being a baby at all. There are no right or wrong feelings, just what you feel yourself.

### ***When will my periods return to normal?***

It may take a while for your periods to get back to normal. Some women find that they have heavier periods for the first month or two but this usually settles down.

### ***How long will the follow up last?***

Follow up for complete and partial molar pregnancies may be as short as six months from your ERPC approximately 50% of women need to continue follow up for longer than this, depending on when your first normal result is. If you need treatment you will be followed up indefinitely to confirm that your Hcg levels remain normal.

### ***Do I really have to wait six months before trying for another baby?***

For complete and partial moles, the advice is **yes**. You should wait until the follow up is complete to allow time for any hidden cells from the mole to grow again.

If there are any hidden cells your hCG levels will rise and you will require treatment to destroy these cells. A new pregnancy could mask the regrowth of molar cells and make them very difficult to detect and treat.

Six months may feel like a long time but it is needed to ensure that you are safe.

### ***Will I be able to get pregnant again?***

Having a molar pregnancy does not affect your fertility at all and many ladies have gone on to have babies following molar pregnancy.

### ***Will I have another molar pregnancy?***

It is possible but very unlikely. The general risk of molar pregnancy is approximately 1 in 600. If you have

had molar pregnancy your chance of having another one is approximately 1 in 100.

There is an excellent chance that you will go on to have a perfectly normal pregnancy next time.

***Can I go on the Pill while I am being followed up?***

Once your hcg levels have returned to normal, you can use the contraceptive pill, but not before. The reason for this is that the pill can make mole tissue grow and this increases your chance of needing further treatment.

If you do decide to use the pill, you must tell your GP and the follow-up service. THIS IS VERY IMPORTANT.

***What other contraceptives can I use?***

The condom together with spermicide is suitable and highly effective when used as advised.

The coil (IUCD) is best avoided until your hcg levels return to normal.

In the meantime you can get further advice and supplies from your GP or local Family Planning Clinic.

***If I need chemotherapy, will it affect a pregnancy in the future?***

You will be advised to wait for one year after you have finished your treatment before trying to conceive. After that your pregnancies will not be affected by your having had chemotherapy.

***Can my partner 'catch' anything from me because I have had a molar pregnancy?***

No. A hydatidiform mole carries no risk to your partner.

The experience of hydatidiform mole can be very distressing for you and your partner. Not only have you experienced a miscarriage but you also need to have continued medical follow up to have your blood levels monitored.

This can mean a lengthy time of anxiety and worries for the future. It can also feel as if you are 'in limbo', unable to move on after this pregnancy and need to delay trying again.

You may find it helpful to talk to someone who can answer your questions and provide support. Both the Charing Cross and Weston Park centres have a counsellor attached to the follow up service. Please contact the centre and they will be able to put you in touch with the counsellor.

**USEFUL LINKS**

**The Miscarriage Association**

They have a telephone helpline, a volunteer support service, an online support forum and a range of leaflets on pregnancy loss.

**HELPLINE ; 01924 200799**

**[www.miscarriageassociation.org.uk](http://www.miscarriageassociation.org.uk)**

**17, Wentworth Terrace,  
Wakefield  
WF1 3QW.**

**You may also find some of the websites helpful;**

[www.molarpregnancy.co.uk](http://www.molarpregnancy.co.uk)

[www.hmole-chorio.org.uk](http://www.hmole-chorio.org.uk)

[www.chorio.group.shef.ac.uk](http://www.chorio.group.shef.ac.uk)

You can get further information on all sorts of health issues through NHS interactive available through Sky TV or online at: <http://www.nhsdirect.nhs.uk/>

For Health advice and out of hours GP service please call Island Health Line on 0845 6031007

### **We Value Your Views On Our Service**

If you wish to comment on the care which you, your relative or friend has received, we will be pleased to hear from you. Please speak to the person in charge of the ward, clinic or service in the first instance or ask them to contact the Quality Team. If you wish to contact them directly, telephone on 534850.

Alternatively you may prefer to write to:

Chief Executive  
Isle Of Wight NHS Primary Care Trust  
St Mary's Hospital  
Newport  
Isle of Wight  
PO30 5TG

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If you would like help and advice to stop smoking please call: 01983 550386 to talk to Island Quitters,

Ref: **Mat/Molar/01**