

# The Miscarriage Association



*Acknowledging Pregnancy Loss*

## Hydatidiform Mole

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*You have been diagnosed as having a Hydatidiform Mole, also called a Molar Pregnancy. The loss of your baby is likely to make you feel very sad. In addition this may be the first time you have heard of this condition and so you may also feel shocked, confused and anxious about the future.*

*The purpose of this leaflet is to explain fully what a hydatidiform mole is, and why it is necessary for women who have had a mole to be followed up by the hydatidiform mole follow-up service. All the information in this leaflet has been carefully checked. It is important that you understand exactly what has happened to you, and why your doctors may recommend a certain course of action. The meaning of the medical or scientific terms we have needed to use is given at the end of the leaflet.*

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## How a normal pregnancy develops

The sperm meets the egg (or ovum) in the **fallopian tube** which leads out towards the ovary from where the egg came a few days before. The sperm joins the egg and the **fertilised ovum** moves on towards the cavity of the womb itself. During **fertilisation** the genes from the sperm mix with those from the egg to produce the individual features of the baby to be.

Genes, which are found in all of our cells in things called **chromosomes**, contain a system for passing on genetic information in a series of chains of a chemical called DNA. By the time the fertilised ovum has reached the womb, all the information has been exchanged and it has divided into two main groups of cells.

The **trophoblast** is that part from which the placenta (afterbirth) and membranes develop. Another name for this tissue is the **chorion**.

The trophoblast invades the lining of the womb to anchor the pregnancy and allow it to grow. This is called **implantation**. The placenta forms and so does the embryo. After a few weeks it becomes a recognizable baby (or foetus, as it is called while still in the womb). The baby grows and his or her organs gradually become able to function on their own and, after about 40 weeks since the last period, he or she is born.

Many pregnancies, possibly 50 to 60 percent, are lost before they can implant, or within the first three months. This is called a miscarriage. Rarely, other problems can arise and **Hydatidiform Mole** is one of these. The rest of this leaflet describes this rare condition.

## What is a Hydatidiform Mole?

This peculiar name is an old-fashioned term meaning a liquid-filled mass of cells. It arises when the trophoblast (or chorion) grows in a disorganized way to fill the womb at the expense of the embryo. Since it swells to fill the womb, a hydatidiform mole is one of a group of rare conditions called **trophoblastic tumours**. The pregnancies are called **molar pregnancies**. They occur in about 1 in 1200 pregnancies.

There are two types of molar pregnancy: a **complete** and a **partial** hydatidiform mole. Occasionally the mole tissue persists and may start to grow and spread; this is an **invasive** mole. **Choriocarcinoma** is a very rare complication of hydatidiform mole.

### **Complete Mole**

We have noted that an egg and sperm fuse together and share genetic material (DNA). Sometimes the egg cell does not carry any genetic material so that when the sperm fuses with it, no sharing can take place. Usually the fertilized egg dies at that point but, rarely, it goes on to implant in the womb. When it does, no embryo grows, only the trophoblast, and it grows in a disorganized way. This produces the **complete** hydatidiform mole.

### **Partial Mole**

In this situation two sperms fertilise the egg (this should be impossible). There is too much genetic material and, as a result, the pregnancy develops abnormally, with the placenta outgrowing the baby. A foetus may or not be present and even if it is present, it does not develop. There have been some (very few) reports of live babies born after what was thought to be a partial mole, but this may have been the result of an extremely rare condition where a normal baby has a mole for a 'twin'.

### **Invasive Mole**

We have seen that one of the things that trophoblast does normally is to invade into and through the lining of the womb. This is necessary to make the placenta and to hold it in the womb. Sometimes the trophoblast of a complete molar pregnancy invades much more deeply into the womb than it should and, rarely, it can spread. This condition needs to be recognised and treated properly (*described below*).

### **Choriocarcinoma**

In this very rare tumour the trophoblast cells become totally disorganised

and can invade and spread widely. They have, in fact, become cancerous. Some choriocarcinomas follow a complete molar pregnancy, but extremely rarely it can follow some time after normal pregnancy, miscarriage or termination of pregnancy. It is to be emphasised that this is extremely rare. The small risk of choriocarcinoma is the reason that molar pregnancies are followed up. This is also why the follow-up centres are located in units dealing with cancer (oncology) or trophoblastic tumours. They can detect choriocarcinoma very early and the cure rate is almost 100%.

## What do I feel if I am carrying a molar pregnancy?

One of the hormones produced by trophoblast normally is called **human chorionic gonadotrophin** (hCG). One of the functions of hCG is to make the ovary produce its hormones to allow the pregnancy to develop. Most of the symptoms of a molar pregnancy are caused by the massive amount of hCG produced by the overgrown trophoblast. The symptoms will therefore be mainly:

- No periods
- A lot of nausea or vomiting. This can be really troublesome.
- Irregular bleeding from the vagina. The blood may contain little fluid-filled cysts.
- Symptoms like those of a miscarriage between 8 and 16 weeks

The womb is often larger than is expected from your dates and sometimes the hCG causes the ovaries to be enlarged. Rarely, a mole can cause high blood pressure and protein in the urine (**pre-eclampsia** or '**toxaemia**'), which is a dangerous condition of pregnancy.

## How is it diagnosed and treated?

If you go to your doctor and s/he suspects that you have a molar pregnancy, s/he will arrange:

- a very sensitive blood test to measure hCG
- an ultrasound scan
- for you to be seen by the obstetrician/gynaecologist.

If the diagnosis is confirmed, you will be counselled by the gynaecology team. They will advise that you be admitted to hospital and have the mole removed in theatre by a suction instrument passed through the neck of the womb (cervix) while you are asleep under general anaesthetic. This is called **surgical evacuation** of the mole. You will be observed in hospital for 24 to 48 hours, depending on circumstances. **It is important that you understand that this is not a 'termination of pregnancy' or 'abortion'**. In most cases there never was an embryo and even in the partial mole it will not develop. You must be reassured so that you do not feel guilty. You may well still feel sad, however, at the loss of your pregnancy.

The tissue will be sent to the laboratory for examination and you will be told the result. (see also '*How can I best help myself?*')

A series of tests on your blood and urine for hCG will be carried out over the next few months. If any of the mole has been left behind, the level of hCG may not fall or may even increase. In most women the levels of hCG drop fairly rapidly. If your level of (serum) hCG drops to normal (4 IU/L or less) within 8 weeks, you will be followed up for 6 months from the date of evacuation.

If your hCG level takes longer than 8 weeks to drop to normal, then you will be followed up for a further 6 months after your first normal test. If your hCG values remain the same for three successive samples or they start to rise again, you will be recommended for treatment. ***These are general rules, and every woman is treated and carefully assessed as an individual.***

The results of the follow-up will be sent to your GP and your gynaecologist. If you want to know your own results, you can telephone the follow-up service (allow about three days for them to deal with the sample) and they should tell you the result and how you are doing.

The results from your serum and urine are reported as IU/L (International Units of hCG per Litre). The 'normal' serum level is less than 5 IU/L. Once the follow-up is complete there is no reason why you should not become pregnant.

In future pregnancies, an early ultrasound scan, at approximately 8 weeks, may help to reassure you and your doctor. Antenatal care should be shared between your GP/midwife and the hospital.

Approximately 10% of women require additional treatment using drugs (**chemotherapy**). This may involve a stay in hospital during which you will be given a drug or drugs to kill off any remaining molar cells. Treatment is **very** effective and will not normally affect your ability to have more children.

If treatment is recommended, you will be advised by your doctor. Depending on where you live, you will go to Charing Cross Hospital in London or Western Park Hospital in Sheffield.

## What is the follow-up procedure?

There are three main follow-up centres in the UK – London, Sheffield and Dundee. The procedure may vary between centres but is quite simple: the London follow-up procedure is shown here:

1. You will receive a letter from the follow-up centre telling you that you have been registered for the programme.
2. This will be followed a few days later by a small box/packet containing a letter for your local hospital or clinic and a small tube/s for your urine and blood samples.
3. On the date requested you collect a sample of your first urine of the day and place this in the small tube. Next you attend the hospital or clinic for a blood test which will be given to you in a second tube.
4. Both tubes are placed in the box/packet along with a form on which you give details of your last period and any drug treatment you are taking. The box/packet is closed and posted (no stamp is needed). Once the blood tests are normal, only the urine sample will be needed.

## What happens if I have a choriocarcinoma or an invasive mole?

Detecting choriocarcinoma or an invasive mole is the job of the follow-up service, and you will be given clear advice and guidance in the very unlikely event that either of these should occur. Blood samples may be taken from you and your partner to check your blood group and tissue type because they may have some influence on the best treatment. Investigations, e.g. ultrasound, X-ray, CT or MRI scans, may be needed to check the extent of any problem. Treatment is carried out in one of the two treatment centres. Treatment is very successful using drugs (chemotherapy) and once treatment has been completed successfully, further pregnancies are possible. **There is no increased risk of abnormal babies in women who have had chemotherapy.**

## How can I best help myself?

1. Always send the samples requested when they are requested. It is important that your urine samples should be the **first** urine of the day.
2. Do not get pregnant whilst you are on follow-up. Pregnancy will produce hCG also seen if the mole is growing back, making detection of re-growth very difficult. **It is very important to tell the follow-up service if you do become pregnant.**
3. Whilst your hCG values are above normal, do not use the contraceptive pill, because it use may prolong the life of any remaining mole cells. If you want to go on the pill, then wait until you have reached normal hCG levels. Condoms used with spermicidal pessaries, cream or jelly are the only contraceptives recommended during the time that your tests are abnormal. Like all contraceptives, these can be obtained free of charge from your GP or Family Planning Clinic.

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## QUESTIONS AND ANSWERS A Review

### *Do I have cancer?*

If you have a hydatidiform mole or invasive mole, then you do not have cancer. However a small proportion of molar pregnancies can develop into a choriocarcinoma, which is a form of cancer. Fortunately it is a cancer with an excellent cure rate.

### *Am I going to die?*

Most emphatically, **NO**. Women do not die these days from hydatidiform mole or invasive mole and only very rarely from choriocarcinoma.

### *I feel different, having a hydatidiform mole. What can I do?*

This is a very common feeling. There is nothing abnormal about the mole tissue itself. Trophoblastic tissue is found in all pregnancies and is normal. A mole is different only in that the growth of the trophoblast was not 'switched off' at the correct time. It was a pregnancy which did not have a baby to control it. You are the same woman now as you were before.

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

It is best not to use the contraceptive pill when hCG values are raised. 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 are normal. You can use the Pill once your hCG values return to normal (see above). In general you are advised to speak to your GP or Family Planning Clinic.

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

Follow-up for **complete** and **partial** moles may be as short as 6 months but could be for up to 1 year, sometimes longer. Approximately 50% of women fall into each group. If you need treatment, then you will be followed up indefinitely to confirm that your hCG values remain normal.

### ***Can I get pregnant again?***

Yes. A molar pregnancy does not effect your fertility at all. Many women have gone on to have babies following a molar pregnancy.

### ***Will I have another hydatidiform mole?***

It is possible, but very unlikely. The odds against a woman who has never had a mole having one are approximately 1 in 1200. If you have had one mole, the odds increase to about 1 in 80. If you have already had two moles, the risk of a third is approximately 1 in 6. **What you must remember is that the chances are still excellent that you will have a perfectly normal pregnancy.**

### ***Am I more likely to have a miscarriage?***

We do not know for certain, but the answer is 'probably no'.

### ***If I need chemotherapy, do I have a greater risk of having a deformed baby in a future pregnancy?***

If you wait for one year after chemotherapy finishes, we can say 'no' with confidence.

### ***Do I have to wait six months before becoming pregnant again?***

For **complete** and **partial moles** the answer is 'normally, yes'. You have to wait 6 months in order to allow time for any hidden cells from the mole to start to grow again. If there are any, then your hCG values will rise and treatment will be given to kill the cells. Six months may seem like a long time to wait, but it is to make sure that you are safe. Do not be tempted to become pregnant before it is safe for you to do so.

### ***Can I do anything to reduce the risk of another mole?***

No.

### ***Can my partner catch anything from me because I have had a mole?***

No.

## **Finally**

We understand that the experience of hydatidiform mole can be very distressing. Not only have you lost your baby, but also you need to be in continued medical follow-up to have your hCG levels monitored. This may mean a lengthy time of anxiety. It can also feel like being “in limbo”, unable to move on after this pregnancy and having to delay trying again. You may find that family and friends don't understand what you are going through and this can make you feel quite isolated.

If you would like to talk to someone else who has been through a molar pregnancy and who can offer support, please contact us at The Miscarriage Association. We will always try to help.

# MEDICAL TERMINOLOGY

We have tried to use as few medical or scientific terms as possible in this leaflet. Here you will find an explanation for those that we have used and some others you may have come across during your care.

## ***Assay (test)***

Scientists use the term assay when they measure something chemically. hCG tests are assayed.

## ***D&C***

These letters stand for Dilatation and Curettage. This is a minor operation in which the opening to the uterus (the cervix, or the neck of the womb) is dilated (made larger) and the lining of the uterus is scraped, using a sharp instrument called a curette. When used early in pregnancy it may be called 'Evacuation of Retained Products of Conception' (ERPC).

## ***Embryo***

The baby in the early stages of pregnancy

## ***Foetus***

Unborn child

## ***hCG***

Human Chorionic Gonadotrophin. This is the major pregnancy hormone. It is produced by the trophoblastic cells. hCG is used in pregnancy test kits and is the hormone which the follow-up service monitors after a molar pregnancy. Biologically, the function of hCG is to maintain the pregnancy.

## ***Metastasis***

The process by which a cancer spreads. It literally means 'to go to another place'.

## ***Mole***

A mass of cells. The commonest 'moles' are the dark-coloured patches often found on the skin, which are masses or moles of dark-coloured skin cells. A hydatidiform mole is a mass of trophoblastic cells. The two are not related in any way.

## ***Placenta***

The placenta is the organ through which the foetus is fed, and by which waste products are removed.

## ***Trophoblast***

The trophoblast or chorion is the thin layer of cells which separate the mother from the foetus.

## ***Tumour***

Literally, a swelling, a tumour is very similar to a mole. Any mass of cells found in the wrong place can be described as a tumour. It does not necessarily mean that the cells are cancerous. It can be benign (non-malignant).

## ***Uterus***

The womb. This is the muscular organ in which the foetus develops. It is lined by a thin layer of tissue called 'endometrium'. This allows the fertilized egg to implant and the foetus to grow. It is the cells of the endometrium which break down each month to cause your monthly period.

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