

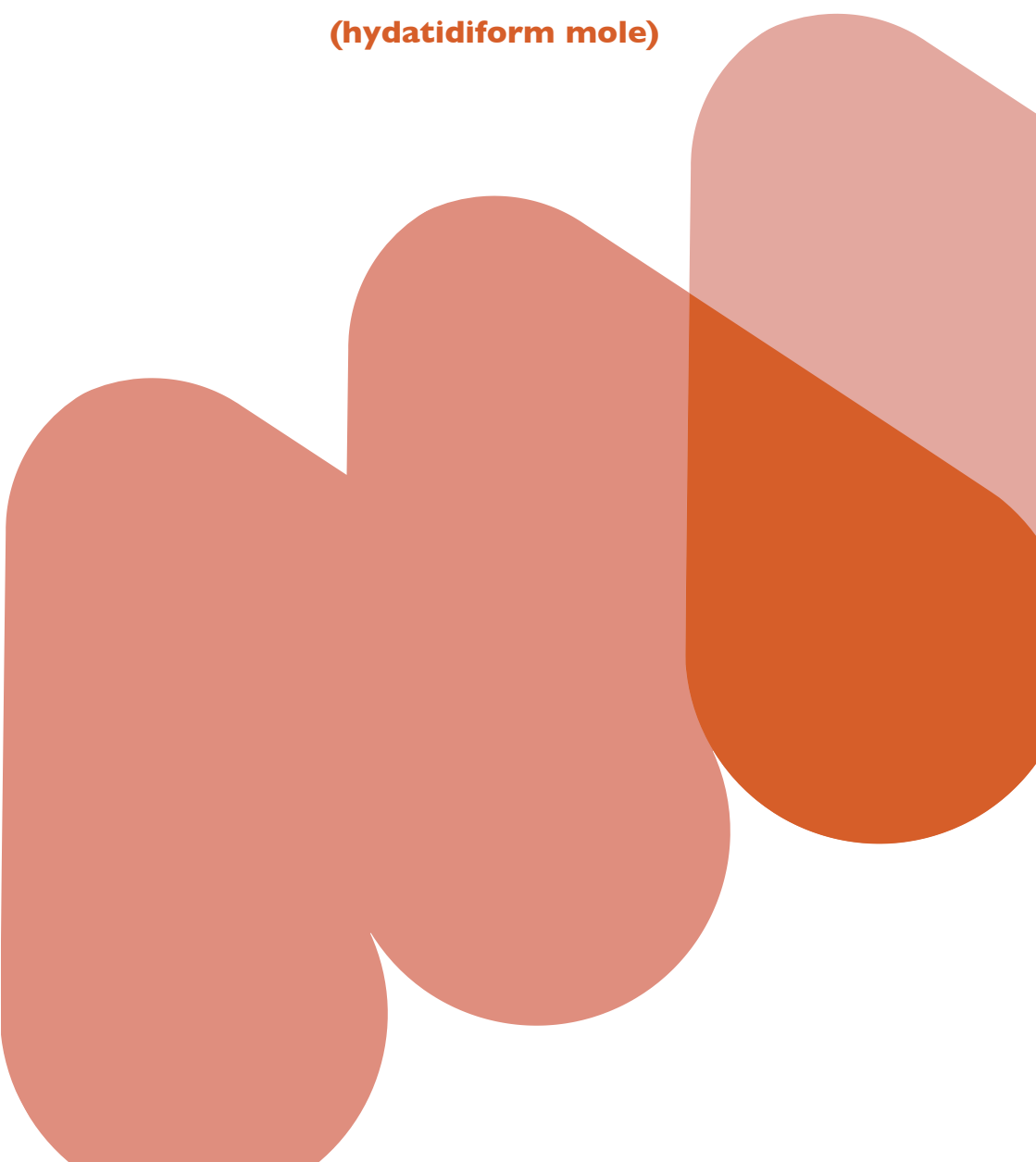


MISCARRIAGE
ASSOCIATION

The knowledge to help

Molar pregnancy

(hydatidiform mole)



We have written this leaflet for women and their partners who have been affected by a molar pregnancy (also called a hydatidiform mole).¹

You may never have heard of this condition and people around you probably won't have either. You might well be feeling confused, upset and anxious – perhaps especially if you have been searching on the Internet.

And of course, you may also be grieving for the loss of your baby.

In this leaflet, we aim to explain:

- what a hydatidiform mole is
- why follow-up is necessary and
- what that follow-up involves.

We will also look at some of the thoughts, feelings and reactions of other women and their partners who have been through molar pregnancy themselves.

“ My doctor didn't seem to know what hydatidiform mole was. I looked it up on the Internet and nearly scared myself witless. ”

¹ We hope it will also be helpful for family, friends and health professionals

What is a hydatidiform mole? What does it mean?

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 where the embryo would normally 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 in pregnancy).

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

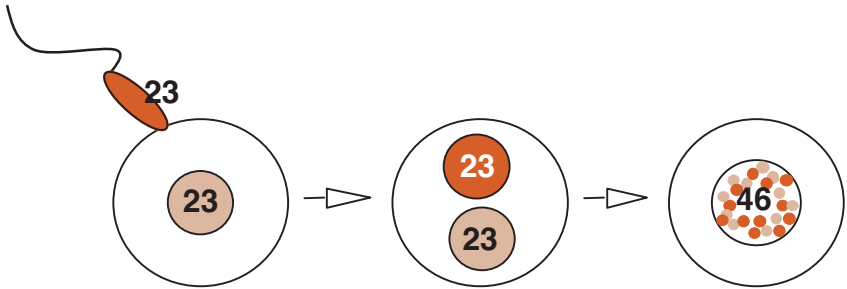
About one in 600 pregnancies is a molar pregnancy. That means it is quite rare, especially compared with miscarriage, which affects around one in four pregnancies.

A hydatidiform mole may be either **partial** or **complete**, depending on the genetic make-up of the fertilised egg. The easiest way to explain this is to look first at what happens in a normal conception.

Normal conception

Each of our cells contains 23 pairs of chromosomes, where one of each pair is from the mother and the other from the father.

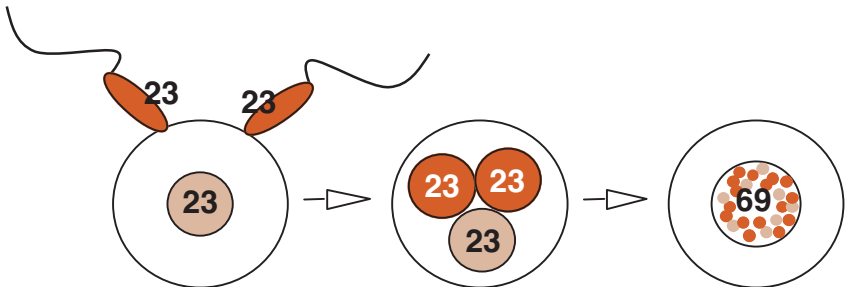
In a normal conception, a single sperm with 23 chromosomes fertilises an egg with 23 chromosomes, making 46 in all.



Partial mole

In this situation, 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, with the placenta outgrowing the baby.

There may be evidence of a fetus but it will be abnormal and cannot survive.

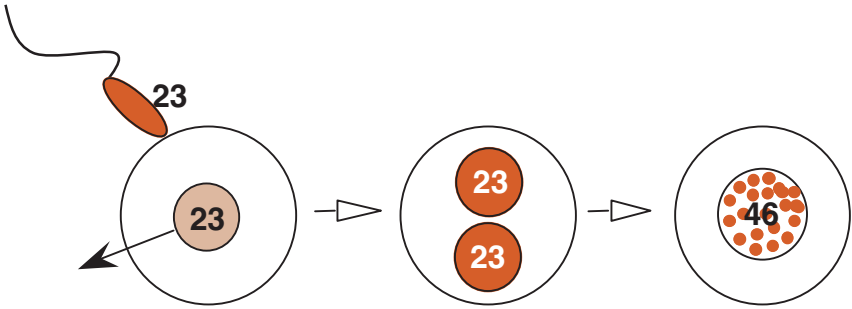


There have been some (very few) reports of live babies born after what was thought to be a partial mole, but this may have been the result of an extremely rare condition where a normal baby has a mole for a "twin".

Complete mole

A complete mole is when one (or even two) sperm fertilises an egg cell which has no genetic material inside. Even if the father's chromosomes double up to make 46 in all, the balance of chromosomes from the mother and father is wrong.

Usually the fertilised egg dies at that point but in rare cases it goes on to implant in the uterus. When it does, 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 about 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**.

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 the follow-up centres are located in units dealing with cancer (oncology) or trophoblastic tumours. They can detect trophoblastic disease very early and the cure rate is almost 100%.

You can read more about the follow-up procedure on page 9.

Signs and symptoms of molar pregnancy

Some women will 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 they can be very like the usual symptoms of pregnancy or miscarriage.

If you have never been pregnant, or have not had particularly strong pregnancy symptoms before, it can be hard to know what is normal and what isn't.

Signs 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 like those of a miscarriage, including pain and bleeding

Your doctor may notice other changes that suggest molar pregnancy:

- Your uterus may be larger than expected from your dates
- Your ovaries may be enlarged (due to the high levels of hCG)
- You might have high blood pressure and protein in your urine, though this is rare.

“**The level of hCG in my body was far beyond anything normal. That explained why I had been feeling so unwell.**”

Diagnosing molar pregnancy

After a miscarriage

Most cases of molar pregnancy are diagnosed after what appears to be a “normal” miscarriage where the woman has had surgical management of her miscarriage. You might hear this procedure referred to as an ERPC, an “evac” or a D & C.

In most hospitals, a sample of the tissue that is removed is sent to the laboratory and tested to see if it is normal pregnancy tissue. (This process is called histology and you may be asked to give your permission). This examination can identify molar tissue and thus a molar pregnancy.

There may be a delay between when you have the surgery and when you are told that you have (or might have) a molar pregnancy. It may be some days or a few weeks after your miscarriage when you are contacted by letter or telephone. You may be asked to return to see the doctor before you are told any more.

“ I thought nothing could be more devastating than losing a baby, until a month later when they told me it was a partial molar pregnancy. ”

“ It was painful to realise that for all these weeks there wasn't a baby growing inside me. It felt like we had been tricked. ”

In pregnancy

In some cases, the GP or hospital doctor might suspect a molar pregnancy. If so, s/he might refer you for one or more of the following:

- A blood test, to measure your hCG levels (this might be done more than once over a few days)
- An ultrasound scan (unless you have just had one)
- An appointment with a hospital gynaecologist or Early Pregnancy Unit

If your doctor diagnoses or strongly suspects a molar pregnancy s/he will recommend that you have surgery to remove any pregnancy tissue. The diagnosis will then be confirmed by laboratory examination.

It is very important that you understand that this process is **not** a termination of pregnancy (an abortion). In most cases there never was an embryo or it died at a very early stage, and even in a partial mole it will not develop. Even so, you may still feel a sense of loss for what would have been your baby.

What happens next?

All women who are diagnosed with molar pregnancy are followed up to check that their hCG levels drop back to normal.

The hCG levels are tested every two weeks 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 you have a **complete mole** and your serum hCG drops to normal (4 IU/L or less) within eight weeks, you will then be followed up for a total of six months from the date of your miscarriage surgery.

If it takes longer than eight weeks, then you will be followed up for six months from your first normal serum hCG.

If you have a **partial mole**, confirmed on review at your follow-up centre, you will be followed up until your serum hCG returns to normal, confirmed with a urine sample four weeks later.

You will be advised not to get pregnant while you are still in follow-up.

If your hCG level:

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

then your doctor will recommend treatment.

About one in ten women need additional drug treatment (chemotherapy) to kill off any remaining molar cells.

Treatment is **very** effective and will not normally affect your chances of having a child in the future.

“ It is now nine weeks since I lost my baby and my levels have not yet dropped to normal, so I have missed the short follow-up. ”

Who does the follow-up?

Depending on where you live, your follow-up will be done at one of the three specialist centres in the UK:

- Charing Cross Hospital in London
- Weston Park Hospital in Sheffield or
- Ninewells Hospital Dundee

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 these on.

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

The procedure may vary a little between the three centres, but not a great deal. As most women are followed up by Charing Cross Hospital in London, we describe their procedure here:

1. You will receive a letter from the follow-up centre telling you that you have been registered for the follow-up programme.
2. A few days later you will receive a small box or packet containing a letter for your local hospital or clinic and a small tube or tubes for your blood and urine samples.
3. On the date requested, you collect a sample of your first urine of the day and place this in the small tube. You then attend the hospital or clinic for a blood test, and the blood will be put into a second tube.
4. You put both tubes in the box or packet that you received, along with a form on which you give details of your last period and any drug treatment you are having. You then close and post the packet (no stamp is needed).
5. Once your blood tests are normal, you will only need to send a urine sample, so you can send them from home, without having to go to the hospital or clinic.

“ I was monitored for six months and thankfully my levels went down quickly. I also attended one of the support group sessions at Charing Cross Hospital, which was very helpful. ”

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 do have either, the staff at your follow-up centre will give you clear advice and guidance.

They will tell you if you need further investigations, such as ultrasound, X-ray, CT or MRI scans.

You will have your treatment in either Charing Cross or Weston Park Hospitals.

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

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

“ Even having a tiny risk of developing cancer is terrifying, especially when it has all stemmed from something as happy and pure as trying to have a baby. ”

How can I best help myself?

- Always send the samples requested on the date requested – don't put it off!
- Make sure that your urine samples are the **first** urine of the day, as this is when hCG levels are at their most concentrated (just like when you do a pregnancy test).
- Avoid getting pregnant while you are in follow-up. Pregnancy produces hCG, so it will be very difficult to know whether increasing hCG levels are from the pregnancy or from molar tissue growing again.
- If you **do** become pregnant, it is very important to tell the follow-up service.
- After your miscarriage surgery, you can use the contraceptive pill even before your hCG returns to normal.

“ When I first realised I would have to wait (before trying again), I cried for about a week. Life seemed so unfair and to have no control over when I could try for a baby was awful. I now feel much better and stronger. I would rather be safe and well for my 3 year old daughter than risk damaging my health. ”

Frequently asked questions

Do I have cancer?

If you have a hydatidiform mole that has gone without needing 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.

Am I going to die?

Women do not die these days from hydatidiform mole or invasive mole and only extremely rarely from choriocarcinoma.

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

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 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 and wrong feelings, just what you feel yourself.

Will I have normal periods during follow-up?

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 a partial mole might be as short as two to three months from the date of your miscarriage surgery. However, some women will continue follow-up for longer than this, depending on when they get their first normal result. If you need treatment, you will be followed up indefinitely to confirm that your hCG levels remain normal.

Do I really have to wait before trying for another baby?

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

If there are any hidden cells, then your hCG levels will rise and you will be given treatment to kill the cells.

A new pregnancy could mask the re-growth of molar cells and make them very difficult to detect and treat.

It may feel like a long time to wait, but it is to make sure that you are safe.

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

Yes. We used to advise women not to use the contraceptive pill during follow-up, but research has shown this isn't necessary.

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; and the cap may be problematic as your measurements may change.

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

Will I be able to get pregnant again?

You should be able to. A molar pregnancy does not affect your fertility at all and many women have gone on to have babies following a molar pregnancy.

Will I have another molar pregnancy?

It is possible but very unlikely. The general risk of molar pregnancy is around one in 600. If you have had a mole, your chance of having another is around one in 100. If you have two molar pregnancies, your chance of a third is around one in 7.5.

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

Am I more likely to have a miscarriage next time?

We don't know for sure, but the answer is "probably no".

If I need chemotherapy, will it affect my baby in a future pregnancy?

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

Can I do anything to reduce the risk of another molar pregnancy?

Not as far as we know. A molar pregnancy is a chance event, not something you have any control over.

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

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



Finally

The experience of hydatidiform mole can be very distressing. Not only have you experienced a miscarriage but you also need to be in continued medical follow-up to have your hCG levels checked.

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 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 lonely and isolated.

You may find it helpful to talk to someone who can answer your questions and provide support. The Charing Cross, Weston Park and Ninewells centres each have a counsellor attached to the follow-up service. Just contact the centre where you’re registered and they will put you in touch with the counsellor.

Information and support

The Miscarriage Association

has a telephone helpline, live chat, and support volunteers, some with personal experience of molar pregnancy. We also have a ‘molar pregnancy’ board on our online forum and range of helpful leaflets.

Tel: 01924 200799

www.miscarriageassociation.org.uk

You may also find some of the following websites helpful:

www.molarpregnancy.co.uk

www.hmole-chorio.org.uk

www.chorio.group.shef.ac.uk

“ My advice to anyone going through this is to speak to your follow-up centre. They are all specialists and amazingly helpful. Don’t be afraid to ask questions. I found that understanding the whole process, from how a mole is formed right through to the worst possible outcome, was a huge comfort. Understanding what it all meant gave me back a bit of control. ”

Thanks

Our sincere thanks to the following people:

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- Dr Rosemary A Fisher, Honorary Consultant Geneticist, Trophoblastic Tumour Screening and Treatment Centre, Charing Cross Hospital, for allowing us to use her illustrations;
- the women who shared their own experiences of molar pregnancy.

“ The molar pregnancy experience is certainly scary and it can be lonely at times as it’s so rare. But there are people out there who have had it or are going through it and that helps. Although it can seem that there’s no end to the testing, I already see light at the end of the tunnel. ”

Need to talk to someone who understands?

Call our support line on 01924 200799. Monday to Friday, 9am-4pm

Chat with us online at www.miscariageassociation.org.uk

Or email info@miscariageassociation.org.uk



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