The Royal Wolverhampton
NHS Trust

Molar pregnancy (Gestational Trophoblastic Disease)

Gynaecology

The prevention of infection is a major priority in all healthcare and everyone has a part to play.

- **Please decontaminate your hands frequently for 20 seconds using soap and water or alcohol gel if available**
- **If you have symptoms of diarrhoea and/or vomiting, cough or other respiratory symptoms, a temperature or any loss of taste or smell please do not visit the hospital or any other care facility and seek advice from 111**
- **Keep the environment clean and tidy**
- **Let's work together to keep infections out of our hospitals and care homes.**

Introduction

This information leaflet is for women with a definite or suspected diagnosis of molar pregnancy. The purpose of this leaflet is to provide you with information to help your understand your diagnosis or suspected diagnosis:

A molar pregnancy can be a traumatic experience. Try to remember that molar pregnancies are not caused by anything you (or the baby's father) did or did not do. There is support available if you need it.

What is a molar pregnancy?

A molar pregnancy is one of a number of different conditions that are called Gestational Trophoblastic Disease (GTD). Gestational Trophoblastic Disease is an umbrella term used to cover the range of conditions that happen when a pregnancy does not develop normally from the very beginning. GTD includes complete molar pregnancy, partial molar pregnancy and other much rarer conditions.

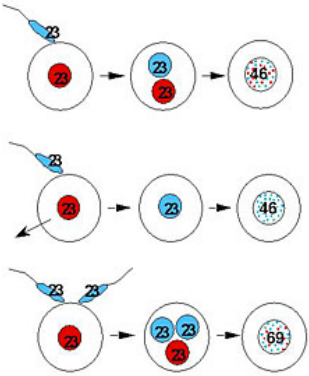
Molar pregnancy (also called hydatidiform mole) is the most common kind of trophoblastic disease. Molar pregnancy occurs when the pregnancy does not develop properly. In healthy pregnancies, an embryo (baby) develops when a sperm fertilises an egg and the genetic material from each combines to produce a baby which has half of its genes from each parent. A molar pregnancy is abnormal from the very moment of conception as a result of an imbalance in the number of chromosomes supplied from the mother and the father. There are two kinds of molar pregnancies:

Complete mole: There is, unfortunately, no developing baby with a complete molar pregnancy. Complete moles usually occur when a single sperm fertilises an 'empty' egg which has no genetic material inside, and then divides to give the fertilised egg a normal number of chromosomes, all of which have come from the father. Complete moles can also occur when two sperms fertilise an 'empty' egg.

Partial mole: There may be early signs of development of a baby, however this will always be abnormal and, unfortunately, cannot survive. Partial moles occur when two sperms fertilise a normal egg and the developing pregnancy has three sets of chromosomes or more.

How do molar pregnancies occur?

Genetic status in normal conception and molar pregnancy



- **Normal conception**
- 2 sets of genes
- 1 paternal
- 1 maternal
- Viable foetus

- **Complete Mole**
- 2 sets of paternal genes
- no maternal genes
- No foetus

- **Partial mole**
- 3 sets of genes
- 1 maternal
- 2 paternal
- non-viable foetus

What is known about the cause of molar pregnancies?

Although some studies have linked molar pregnancy with dietary or genetic factors, the real cause of molar pregnancy is still unknown.

How common is molar pregnancy?

Molar pregnancies are rare, happening with roughly 1 case for every 600 pregnancies in the UK. Molar pregnancy is more likely to develop in women of Asian origin, teenagers and women over 40 years.

When might a molar pregnancy be suspected?

If you have a molar pregnancy, you may have irregular or heavy bleeding from the vagina or excessive morning sickness (hyperemesis). Your uterus (womb) may feel larger than your midwife or doctor would expect in early pregnancy. Less commonly, you may develop raised blood pressure, symptoms of an overactive thyroid gland or abdominal pain because of large ovarian cysts.

If your doctor suspects that you may have a molar pregnancy, you will be referred to an early pregnancy clinic for an ultrasound scan. A blood test which measures the amount of the pregnancy hormone human chorionic gonadotrophin (hCG) may also raise the suspicion that you have a molar pregnancy. Usually, the levels of this hormone are much higher than would be expected in a healthy pregnancy.

How is a molar pregnancy diagnosed?

Pelvic ultrasound scan: Complete molar pregnancies can be strongly suspected on an ultrasound scan because they have a particular appearance on scan. Partial molar pregnancies are harder to diagnose on ultrasound scan.

Testing of pregnancy tissue (histology): The only definite way to diagnose a molar pregnancy is to examine the pregnancy tissue in the laboratory. Most molar pregnancies are diagnosed in this way after you have had surgical treatment for miscarriage. At the end of the procedure, the pregnancy tissue that has been removed is sent to be examined, with your permission. It may take few weeks for these results to be processed. If molar pregnancy is diagnosed, you will be informed.

In other cases when a miscarriage occurs or a termination is performed for some other reason, the tissue sent to the laboratory may demonstrate that a molar pregnancy has occurred, even when one was not suspected.

How is a molar pregnancy treated?

The initial treatment for a molar pregnancy is to remove the tissue from the uterus with an evacuation (D and C) under general anaesthesia. In this procedure, the cervix is dilated in order to allow a suction curette to enter the uterus and remove the abnormal tissue. In some cases of partial molar pregnancy, the molar tissue may be removed by a medical evacuation with oral or vaginal tablets used to empty the uterus.

Separate leaflets are available explaining these procedures in detail.

The choice about which treatment is best for you will be made together with your doctor. This will be based on the risks and benefits of the treatment and individual circumstances.

What happens if I have a Rhesus negative blood group?

If you have a Rhesus negative blood group, you may be given medication known as anti-D to prevent your blood system from developing antibodies which may affect the blood cells of any future babies. You will be informed if this is necessary.

What happens after the initial treatment and what follow up will I need?

If the tissue sample sent to the Histology Laboratory confirms that you have had a molar pregnancy, we will contact you and arrange an outpatients appointment to discuss the results and follow-up procedure. In the UK, all women who have had a molar pregnancy are asked if their details can be registered with a specialist centre so that treatment can be coordinated and provided by doctors who are experts in this field. These centres are in hospitals in London, Sheffield and Dundee.

After registering with a specialist centre, you will be followed up for at least 6 months. Follow-up involves measuring the pregnancy hormone hCG, either in blood or urine specimens.

The specialist centre will post the kit you need to you but you will have your blood test done at your General Practitioner (GP) surgery or local hospital. If you are asked to give a urine specimen, written information will be given on how to do this. If your level of hCG is falling, then the number of abnormal cells in the uterus is also falling and no further treatment is needed. If however, the hCG levels do not fall sufficiently, further treatment may be required and will be explained to you by the specialist centre you are registered with.

Why are molar pregnancies followed up?

Occasionally, the molar tissue may persist and grow deeper into the wall of the uterus and spread; this is an invasive mole. Very rarely, a hydatidiform mole can develop into a choriocarcinoma which is a form of cancer (gestational trophoblastic neoplasia (GTN) and the cure rate is very high at almost 100%. This is the reason why molar pregnancies are followed up. At present, there is no accurate way of predicting immediately after the evacuation who will need further treatment, so it is the policy in the UK that all women who have had a molar pregnancy enter the surveillance programme.

The length of follow-up will depend on your individual needs. This programme of registration and follow-up has produced high cure rates (98 -100%) and very low rates of progression to more serious forms of GTD.

What if I need further treatment?

The majority of women who have a molar pregnancy will not need any further treatment after the initial suction evacuation procedure. However, approximately 15% of women with complete molar pregnancy and around 1% with partial molar pregnancy will require additional treatment.

The two main reasons patients need further treatment are because either the hCG level starts to rise or reaches a plateau or because there is heavy vaginal bleeding.

The two choices of treatment are a further surgical evacuation procedure or chemotherapy treatment. The majority of patients are treated with chemotherapy, as this has a much higher success rate. Fortunately, the overall cure rate for women who need treatment after a molar pregnancy is over 99%.

What type of contraception should I use?

You will need to discuss contraception with your GP or Consultant. Condoms or caps may be used. It is fine to use oral contraceptives. The coil is best avoided until your hCG levels return to normal.

When can I get pregnant again?

Having a molar pregnancy does not affect your chance of having another baby; however, you should try not to get pregnant again until your follow-up programme is complete. For most women, this will be approximately 6 months.

If you develop GTN, you should not get pregnant for 12 months after your chemotherapy is complete because up to 3 in 100 women (3%) may experience a return of the GTN. This is detected by a rising hCG level, usually in the first year of follow-up.

Will I have another molar pregnancy?

It is rare to have a second molar pregnancy; the vast majority of women go on to have normal pregnancies following a molar pregnancy. The risk of a molar pregnancy happening again is 1 in 80. This means that for more than 98 out of 100 women (98%), their next pregnancy will not be a molar pregnancy.

GTD can sometimes recur after a subsequent healthy pregnancy, so you should contact the specialist centre 6 to 8 weeks after all future pregnancies, whatever the outcome, and arrange for a further hCG blood or urine test.

How can I best help myself?

- Always send the requested samples as specified on letter from specialist centre, on the date requested – do not 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 at the end of the pregnancy, as they need to check your urine sample around 6-8 weeks after the end of the pregnancy (including miscarriage) to ensure the hCG hormone has returned to normal.

What happens in Twin Pregnancy with Molar Pregnancy?

Rarely, a woman can have a twin pregnancy where one pregnancy is normal and the other is a molar pregnancy. The outlook for such pregnancies is poor. Approximately, one in four of these pregnancies end with a live baby.

The risks associated with such a pregnancy include:

- Miscarriage
- Preterm delivery
- High blood pressure in pregnancy.

If your doctor suspects that you have this type of twin pregnancy, this will be discussed with you and your pregnancy care will involve the input of a centre specialising in the treatment and follow up of a molar pregnancy.

Where can I get information and support from?

The experience of hydatidiform mole can be very distressing. Not only have you experienced a miscarriage, 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 do not 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 specialist centres at Charing Cross Hospital in London and Weston Park Hospital in Sheffield have a counsellor attached to the follow-up service. Just contact the centre where you are registered and they will put you in touch with the counsellor.

The Miscarriage Association has a telephone helpline, a volunteer support service, an online support forum and a range of helpful leaflets on pregnancy loss. Helpline: 01924 200799

Website: 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

Our contact details:

Bereavement nurse - 07917398313

Emergency Gynaecology Assessment Unit
01902 694606/8362 (Monday to Friday 09:00 until 17:00 excluding bank holidays)

References

RCOG guideline The Management of Gestational Trophoblastic Disease (September 2020) and RCOG Gestational Trophoblastic Disease Patient Information Leaflet

Miscarriage association – Molar pregnancy patient information leaflet

Molar pregnancy- Gestational Trophoblastic Disease: Information for patients. Sheffield, UK. http://stdc.group.shef.ac.uk/resources/patinf2017.pdf

English

If you need information in another way like easy read or a different language please let us know.

If you need an interpreter or assistance please let us know.

Lithuanian

Jeigu norėtumėte, kad informacija jums būtų pateikta kitu būdu, pavyzdžiui, supaprastinta forma ar kita kalba, prašome mums apie tai pranešti.

Jeigu jums reikia vertėjo ar kitos pagalbos, prašome mums apie tai pranešti.

Polish

Jeżeli chcieliby Państwo otrzymać te informacje w innej postaci, na przykład w wersji łatwej do czytania lub w innym języku, prosimy powiedzieć nam o tym.

Prosimy poinformować nas również, jeżeli potrzebowaliby Państwo usługi tłumaczenia ustnego lub innej pomocy.

Punjabi

ਜੇ ਤੁਹਾਨੂੰ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਰੂਪ ਵਿਚ, ਜਿਵੇਂ ਪੜ੍ਹਨ ਵਿਚ ਆਸਾਨ ਰੂਪ ਜਾਂ ਕਿਸੇ ਦੂਜੀ ਭਾਸ਼ਾ ਵਿਚ, ਚਾਹੀਦੀ ਹੈ ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਸਾਨੂੰ ਦੱਸੋ।

ਜੇ ਤੁਹਾਨੂੰ ਦੁਭਾਸ਼ੀਏ ਦੀ ਜਾਂ ਸਹਾਇਤਾ ਦੀ ਲੋੜ ਹੈ ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਸਾਨੂੰ ਦੱਸੋ।

Romanian

Dacă aveți nevoie de informații în alt format, ca de exemplu caractere ușor de citit sau altă limbă, vă rugăm să ne informați.

Dacă aveți nevoie de un interpret sau de asistență, vă rugăm să ne informați.

Traditional Chinese

如果您需要以其他方式了解信息，如易读或其他语种，请告诉我们。

如果您需要口译人员或帮助，请告诉我们。

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