

Gestational Trophoblastic Disease service

Molar pregnancy – follow-up

Information for patients, relatives and carers

Introduction

This leaflet is designed to give you information about the follow-up programme for molar pregnancy following an evacuation after a miscarriage. It covers both complete molar pregnancy and partial molar pregnancy.

It is not meant to replace the discussion with your healthcare team, but hopefully acts as a useful reference point for the information discussed. If you have any questions, please do not hesitate to contact the team on the number or email provided at the end of this leaflet.

What is a molar pregnancy?

In normal conception of pregnancy, a single sperm successfully fertilises a single egg. There are two sets of genes – a paternal set from the sperm, and a maternal set from the egg. In molar pregnancy, this does not happen.

In a partial molar pregnancy, two sperm fertilise a single egg. This results in a conception with three sets of genes – two sets from the father (paternal) and one from the mother (maternal). In a partial molar pregnancy, the foetus develops abnormally and will never survive (non-viable).

In a complete molar pregnancy, one sperm will fertilise one egg and duplicate its genetic material to give two sets of genes which both come from the father – there will be no maternal genes. Here there is no foetus at all – instead the placenta grows as a series of grape-like sacs full of liquid (cysts).

Normal conception: Two sets of genes, 1 paternal and 1 maternal = **normal foetus**

23 maternal
23 paternal

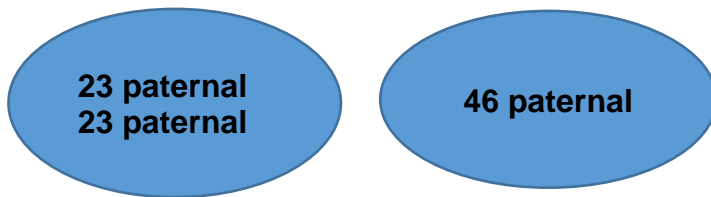
46 maternal
and paternal

Partial mole: 3 sets of genes, 2 paternal and 1 maternal = **non-viable foetus**

23 maternal
23 paternal
23 paternal

69 maternal
and paternal

Complete mole: 2 sets of genes but both are paternal, no maternal genes present = **no foetus**



We do not know exactly what causes a molar pregnancy, but we do know that the pregnancy is not normal at the time of fertilisation. Molar pregnancy is very rare – for every 1000 live births registered in the UK only two molar pregnancies are registered.

Why do I need follow-up?

After an evacuation to remove a molar pregnancy, there is always a risk of molar tissue remaining in the uterus. This can then grow and spread. We do a series of tests (urine or blood, or both) following a molar pregnancy to check whether molar tissue is still present.

Molar tissue can remain in about 10% of women. This condition is curable, and treatment can be given if needed. Treatment does not normally affect fertility.

If test results show you need treatment, you will need to come to Charing Cross hospital for specialist treatment. You will remain under the care of your local gynaecologist throughout. If you do not require specialist treatment you will be monitored via remote follow-up and will not need to visit Charing Cross hospital.

How does the follow-up work?

You will be sent a sample kit containing two tubes. One is for a urine test and the other is for a serum test. Serum is a fluid which we collect via a blood test

1. You can collect your urine sample at home. Follow the instructions in the kit.
2. You will need to have your blood test at your GP surgery or local hospital. Please check with your GP or local hospital if you need to book an appointment to have this blood test done.
3. Take the sample kit with your urine sample to your blood test. There is paperwork inside the kit with instructions for your GP or local hospital. This will tell them about your blood test and how they need process it.

If you have the blood test done at your GP, the surgery will need to send the sample (along with your urine sample) to your local hospital via their collection service. The local hospital will then separate the serum from your blood and should send us the samples. The local hospital must send us both samples in the box provided – no stamp is needed within the UK.

You can see the process explained in a video at: <https://youtu.be/sBagwWqZTEU>

If you come across problems getting your blood taken or processed, please ask the surgery or local hospital to call us on 020 3311 1409.

How do I get the results of my follow-up tests?

Allow at least 3 working days for the results to be ready

Please call us for your results on 020 3311 1409.

We are open between 9:00-13:00 and 14:00-16:00, Monday to Friday. Please note that some results will not be available until after 15:00.

Please call us to find out your screening blood or urine test results. We will not usually call you.

What is the follow-up schedule?

HCG (human chorionic gonadotrophin) is the pregnancy hormone produced by trophoblast cells that form at part of the placenta.

- you will need to have blood and urine tests every two weeks until your HCG result returns to normal.
- normal HCG values in blood is less than 5 (<5) and in urine less than 25 (<25)
- HCG is measured in international units (IU) per litre. You may see this written as IU/l

Complete molar pregnancy

If your test results show normal HCG levels within 56 days of the evacuation of your molar pregnancy, you will need just one more blood sample to confirm the normal reading before being discharged from the service.

If it takes more than 56 days for your HCG level to return to normal, you will be on a longer follow-up programme. This will be for 6 months after levels have normalized. You will need to give monthly urine samples.

Partial molar pregnancy

Once your HCG levels have returned to normal, we will need you to provide a further urine sample four weeks later. Follow-up will then be complete.

Should I be concerned about cancer?

Molar pregnancy can be a pre-cancerous condition that requires a set period of testing. This is monitored with blood and urine tests. If your molar pregnancy has become a cancerous condition that requires chemotherapy treatment, the clinical team will discuss this with you.

A molar pregnancy not requiring treatment with chemotherapy is a non-cancerous condition.

When can I try to get pregnant again?

You can try for a baby once your follow-up is complete. The reason we ask you to wait is that occasionally, molar tissue cells which are dormant (undetectable) are triggered into activity by a new pregnancy, so it is safer to wait.

What method of contraception should I use?

It is safe to use most forms of contraception including the pill (oral contraceptive) after molar evacuation. You can do this even before your HCG levels have returned to normal.

Research shows that taking the pill or other hormonal preparations before HCG levels have returned to normal does not increase the risk of an invasive mole developing.

It may be best to avoid using an intrauterine device until monitoring is completed as insertion of the device may cause excessive bleeding.

Can a molar pregnancy happen twice?

A second molar pregnancy is very rare. It happens to just 1 in 100 of women (1%) registered with our service. Most of this risk is for women who have had a complete mole.

Can I do anything to speed up my HCG result going back to normal?

No, it is a biological process. You should avoid the use of cannabis and over-the-counter supplements as these can potentially alter your tumour marker levels.

Bleeding following the evacuation of a molar pregnancy.

After the evacuation of a molar pregnancy, it is usual to have some light bleeding for a week or two. Occasionally this can be longer. The bleeding should usually be no heavier than your regular monthly period and should get less over the course of a few days.

Generally, problems with bleeding are relatively mild, but they can sometimes be serious. It is important that you seek medical advice if you have any concerns, so that either reassurance or the right treatment can be given.

If the bleeding is heavier than your usual period, you should call us on 020 3311 1409 or email ichc.hmole@nhs.net if during working hours.

If it is outside of working hours and you are bleeding heavily, or if you pass clots, feel faint or have abdominal pain, you must go straight to your nearest accident and emergency department.

Some patients who have heavy bleeding will require admission to hospital for monitoring and/or a blood transfusion. Occasionally a drug which controls bleeding may be prescribed.

What can I do to reduce the chances of bleeding after the evacuation?

You can help reduce your chances of bleeding by:

- avoiding strenuous exercise, particularly heavy lifting. You should avoid this until at least a week after any bleeding has settled
- you should not take any painkillers which contain aspirin or non-steroidal anti-inflammatories (for example Ibuprofen). Paracetamol is safe to use
- you should avoid having sex until any bleeding has settled

Emotions and molar pregnancy

Having a molar pregnancy can challenge your emotional and physical well-being. Losing a pregnancy can trigger many different feelings. For some, the emotional healing takes as long as the physical healing, for some it takes longer. Even if the pregnancy ended very early, the feelings of loss can be very difficult to process for both the person who was pregnant and their partner. The experience of grief can be unexpected; you may feel angry or sad, you may feel numb or confused. It is important to know there is no wrong way to feel and there is no wrong time to feel it.

Unexplained miscarriages or a molar pregnancy can be very difficult to understand and accept, and coping with a molar pregnancy in addition can be overwhelming. The body produces all the normal signs of being pregnant, which can be very painful emotionally. It is ok to acknowledge that you conceived, and some people find it helpful to hold a ceremony or memorial for their lost one for closure.

Every relationship is unique, but can be impacted by diagnosis and treatment. Many partners find it very difficult to see their loved one go through miscarriage and molar pregnancy. No two people process and feel the same thing at the same time, so it's important to try to communicate how you are feeling when you can do so. Grief is complicated and the reasons individuals feel how they feel are also unique. Communication, listening and asking for support, whatever that looks like to you, helps each person know that they are not alone, and that help is not only available, but is appropriate.

For some people, thinking about the future can be difficult. It can be frightening to imagine moving forward, or future family planning. It is important for you to know that this is a rare and curable condition, that it is not caused by anything you or your partner have done and when you are ready it will not impact your ability to live a full life or build a family if you wish to do so.

Who can I contact for specialist support?

We have a specialist counsellor supporting the Gestational Trophoblastic Disease Centre. If you are or have been on our follow-up programme and feel that counselling would benefit you or your partner, or both, please call the advisory line for a referral to the counsellor.

How do I contact the team?

You can contact our team on 020 3311 1409 if you have any questions or concerns, or to access your results. Our service is open between 9:00-13:00 and 14:00-16:00, Monday to Friday.

Website: www.hmole-chorio.org.uk

Email: ichc.hmole@nhs.net

Key points

- We do not routinely give you an appointment at Charing Cross hospital unless we are considering initiation of treatment.
- You are being entered onto a screening programme under the remote supervision of Charing Cross Hospital National Screening programme, however, you also remain under the care of your gynaecology team who referred you to Charing Cross hospital.
- If you require your HCG results then you need to call or email the screening team on the number/email address provided in this booklet. We do not routinely call you with results of your screening blood tests or urine.
- We advise you to not get pregnant while on your screening programme
- You will receive kits that are to be used to send blood serum and urine back to us here at Charing Cross hospital. There are instructions inside the box for your local hospital/GP/Clinic to follow. Please highlight this to the team taking the blood sample.
- The kit should be returned to Charing Cross hospital from your local laboratory if it contains a blood sample. You should not have to send it yourself.
- If there are any queries about how the kit should be used, please contact us on the number provided to clarify.

Where can I find extra information and support?

Information sessions

The screening team runs drop-in information sessions every other month. If you would like to join, please call us for more details. These sessions are online.

Miscarriage Association – www.miscarriageassociation.org.uk

Helpline: 01924 200799 (Open Monday, Tuesday, Thursday 09.00 to 16.00, Wednesday and Friday 09.00 to 20.00)

How do I make a comment about my visit?

We aim to provide the best possible service and staff will be happy to answer any of the questions you may have. If you have any **suggestions** or **comments** about your visit, please either speak to a member of staff or contact the patient advice and liaison service (**PALS**) on **020 3312 7777** (10.00 – 16.00, Monday to Friday). You can also email PALS at imperial.pals@nhs.net The PALS team will listen to your concerns, suggestions or queries and is often able to help solve problems on your behalf.

Alternatively, you may wish to complain by contacting our complaints department:

Complaints department, fourth floor, Salton House, St Mary's Hospital, Praed Street
London W2 1NY

Email: ICHC-tr.Complaints@nhs.net

Telephone: **020 3312 1337 / 1349**

Alternative formats

This leaflet can be provided on request in large print or easy read, as a sound recording, in Braille or in alternative languages. Please email the communications team:
imperial.communications@nhs.net

Wi-fi

Wi-fi is available at our Trust. For more information visit our website: www.imperial.nhs.uk

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