North West Anglia
NHS Foundation Trust

Information about Hydatidiform Mole (Molar Pregnancy)

Introduction

Normally during conception, a single sperm with 23 chromosomes fertilizes an egg with 23 chromosomes, making 46 in total.

A **partial mole** is where two sperm (each with 23 chromosomes) fertilize the egg making 46 paternal chromosomes and 23 maternal ones. There is too much genetic material for the baby to be able to develop.

A **complete mole** is where one or two sperm chromosomes fertilize an egg which has lost all or some of its female chromosomes. There is not enough of the right genetic material meaning that the placental tissue will grow very quickly, but abnormally. It often has a cystic appearance. If untreated, a complete molar pregnancy would normally miscarry by 16-18 weeks.

Why did this happen?

There are some studies that suggest diet or genetic factors are a reason, but the real cause is unknown. There appears to be more risk if you are at the start or end of the reproductive age group, for instance, under 15 or over 45 years

What are the signs and symptoms?

The signs are similar to usual pregnancy symptoms although the levels of the pregnancy hormone (hCG) is usually very high causing increased nausea and vomiting. There may be irregular bleeding from the vagina and the womb may contain little fluid-filled cysts. When your tummy is examined the uterus may be larger than expected from your dates and the high levels of hCG hormone may cause your ovaries to be enlarged.

How is a molar pregnancy diagnosed?

A molar pregnancy may be suspected through blood tests (which measure your hormone levels) or an ultrasound scan. Normally we are only sure once the lab have tested a sample of the tissue.

If molar tissue is confirmed by the laboratory, we will ask you to come back to the hospital to discuss what this means, answer any questions you may have and to register you into a follow-up programme

Do I <u>need</u> to have this follow-up?

Molar pregnancies carry a risk of developing into something called ‘persistent trophoblastic disease’ which may need further treatment with chemotherapy. Around 15% of women with a complete molar pregnancy and around 1% of women with a partial molar pregnancy, will need additional treatment. The two main reasons women would need treatment is because their hCG levels are rising, or they have heavy vaginal bleeding. There is no way of predicting who will need further treatment, so it is the policy in the UK that all women enter the follow up programme.

Who carries out this follow-up?
Your follow-up tests will be carried out by one of the three centres in the UK who specialise in molar pregnancy. We normally refer you to Charing Cross Hospital in London, but it is unlikely you will have to go there yourself.

You will be sent a 'testing kit' asking for blood and urine samples to be taken and posted back to Charing Cross hospital who will analyse them and call you with the results. This is repeated every couple of weeks, and it could be 6 months or a year before the monitoring is complete (depending on which type of molar pregnancy you have).

If the level of hCG hormone in your blood is reducing then no treatment is needed. If the level is static or rising then this would suggest that the number of abnormal cells is increasing. You may then need additional treatment.

Is there anything else I can do to help myself?

- Please complete your follow-up and send samples on the dates requested.
- Avoid getting pregnant during this time. Pregnancy produces hCG so it will be difficult to know whether the increasing hormone levels are from the new pregnancy or from the molar tissue growing again.
- If you move home, please let Charing Cross hospital know your new address.
- If your blood hormones don't reduce, and you need further treatment from Charing Cross, you will need to enter the follow-up programme again, whether you have a child or not.

Can I use contraception?
You should avoid pregnancy (see section above) and it is okay to use contraception - with the exception of the contraceptive coil - whilst you are being monitored. Please ask us or your GP if you would like contraception.

Will this happen again?
There is a slight increase of developing another molar pregnancy, however the risk is low at around 1 in 100. We will offer you an ultrasound scan back in our hospital during your next pregnancy when you are around 7-8 weeks, so call us to make this appointment.

Who can support me?
Charing Cross hospital has a counsellor available to patients (and their families) registered with them, and we may be able to offer you counselling here – ask us for more information.

Do I have cancer?
If you have had a molar pregnancy, the majority of the time the problem will disappear on its own and no further treatment is needed. A molar pregnancy on its own is not a form of cancer.

For the approximately 15% of patients who have had a complete molar pregnancy and the 1% of partial mole patients who go on to further treatment, the situation is different. Whilst we generally do not do a further biopsy to prove it, once the hCG level is rising and the decision to start treatment is made, we would regard these

patients as having a very rare form of cancer. We refer to these patients as having 'persistent trophoblastic disease/choriocarcinoma'. There is also a condition called Placental site trophoblastic tumour, which is very rare, with less than 5 women per year diagnosed. This condition is generally diagnosed months or years after a pregnancy.

However the reassuring news is that this type of cancer is completely different from the normal types of cancer and that the cure-rate for patients developing this after a molar pregnancy is over 99%. Any samples/tissue removed during surgery will be sent to the laboratory for checking.

What happens to my pregnancy tissue?
Any samples tested in our laboratory are normally kept for up to 30 years.

Our normal protocol is for foetal tissue to be included in a shared cremation at the local crematorium around 4-8 weeks after your miscarriage. There may be an option for individual burial or cremation or you can chose to take your pregnancy remains home. Please let us know if you prefer not to have your pregnancy remains included in our shared cremation.

Contact Details:

<table>
<tr><td>The Early Pregnancy Unit (EPU)
Treatment Centre,
Hinchingbrooke Hospital,
Huntingdon, PE29 6NT
Opening days may vary</td><td>The Emergency Gynaecology Assessment Unit (EGAU)
1st floor, woman and child unit, Bretton Gate
Peterborough (City Hospital),
PE3 9GZ
Open: Weekdays 0800-1800
Weekends/Bank Holidays 0800-1200</td></tr>
<tr><td colspan="2">Charing Cross Trophoblastic Screening and Treatment Centre
Department of Medical Oncology, Fulham Palace Road,
London W6 8RF

Monday-Friday 0930-1230 and 1400-1700
Telephone: 0208 846 1409

www.hmole-chorio.org.uk</td></tr>
<tr><td colspan="2">Central triage line for EPU and EGAU: 01733 673758 (voicemail will cut in when the line is engaged – please leave a message for a call back).
www.womenshealthpeterborough.co.uk</td></tr>
<tr><td colspan="2">For emergencies only, out of these hours, please attend the Emergency Department.</td></tr>
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Within this leaflet we use the term woman/women, however we acknowledge that it is not only people who identify as women for whom it is necessary to access our services. We recognise the importance of providing inclusive and respectful care to all people and their families, including those whose gender identity does not align with the sex they were assigned at birth. Please let us know if there is anything we can do to make you feel more comfortable while you are under our care.