Gynaecology and Reproductive Medicine

Molar pregnancy (hydatidiform mole)

Information for patients, relatives and carers

Introduction

This leaflet explains what is known as a 'molar pregnancy', how it is diagnosed and treated and what you can expect from us (your clinical team). If you have any questions about the information in this leaflet, or about anything else, please do not hesitate to ask us.

What is a molar pregnancy?

A molar pregnancy arises due to a problem occurring at the time of conception (when the egg and the sperm meet). Either the maternal (female) chromosomes are lost (a complete mole), or there are two sets of chromosomes from the father and one from the mother (a partial mole).

This means the cells are unable to form the placenta and baby of a normal pregnancy. Instead, there is growth of abnormal cells or clusters of water-filled sacs inside the womb. They used to be called a 'hydatidiform mole', but now most people call them 'molar pregnancies'.

In complete moles, there is only molar tissue in the womb. In partial moles, there may be both molar tissue and tissue that looks like the normal start of a pregnancy. Unfortunately, however, the pregnancy cannot continue healthily in either of these cases.

Occasionally, because the growth of this tissue is not under the same checks and controls as normal tissue, it can continue growing, which can be a problem. Very rarely, it can grow beyond the womb. To stop the tissue growing, you may need further treatment. We follow up molar pregnancies very carefully to make sure that we identify which women need this treatment and when. In this way, treatment is very successful, with an almost 100 per cent cure rate.

In the UK, about 1 in 600 pregnancies is a molar pregnancy. Women of certain ethnicities seem to be at higher risk (molar pregnancies are twice as common in Asian women compared to Caucasian women), as are women above the age of 45 years or under the age of 16 years, and those who have had a molar pregnancy before.

How is a molar pregnancy diagnosed?

Sometimes a molar pregnancy is suspected on ultrasound. Diagnosis is only confirmed when tissue from a miscarriage (which may have been passed naturally or removed during an operation) is looked at under the microscope.

What treatment do I need?

If a molar pregnancy is suspected on an ultrasound scan, then we will usually suggest that you have surgical management. This is essentially the same operation that is performed for a miscarriage (please see our surgical management of miscarriage leaflet). If the operation has already been performed, or you had passed the pregnancy tissue naturally, you will usually not then need any further treatment.

Because of the risk of the molar pregnancy tissue continuing to grow, we need to follow things up carefully. We refer all patients to Charing Cross Hospital for follow-up, which is 1 of 3 units in the country with a specialist service for molar pregnancy.

Once we've made the referral, they will contact you within 2 weeks. They will send you urine pots to fill and send back or blood sample pots for you to take to your GP to have blood taken, or both. By monitoring the level of pregnancy hormone, they can check that the levels stay low. For women with complete moles, they follow up for at least 6 months. For women with partial moles, they follow up for at least 4 weeks after a negative hormone test.

If the levels of pregnancy hormone start increasing, or don't drop to normal, then it can be a sign that you need some treatment (chemotherapy – which is just the medical term for using chemicals (or drugs) for treatment). For complete moles, approximately 15 out of 100 women will need additional treatment. For partial moles, the proportion is smaller: approximately 1 in 200. The good thing about doing the monitoring is that the need for any treatment will be picked up early. This treatment is very effective, with an almost 100 per cent cure rate.

Very rarely, the molar pregnancy tissue can become cancerous. This means it grows quickly and can spread to other parts of the body. This condition is known as 'choriocarcinoma'. This sounds frightening but you should be reassured that it is very rare (there are less than 20 cases of this each year in the UK) and that treatment is very successful.

Future pregnancy and contraception

We advise you not to get pregnant again until you have been discharged from follow-up. If you've needed chemotherapy, we ask you to wait a year. It is important that you use a reliable contraception during this time and you should discuss your options with your doctor.

Following any future pregnancies, no matter what the outcome (whether you give birth or have a miscarriage), you should tell the screening centre. Pregnancy hormone levels are measured 6 to 8 weeks after the end of any future pregnancy. This is to rule out another molar pregnancy.

Who you can contact

Once you have been referred to Charing Cross Hospital, you can phone their advisory line on

020 3311 1409 (Monday to Friday, 09.00 to 13.00 or 14.00 to 16.00).

You can access all of our gynaecology leaflets on our website <u>www.imperial.nhs.uk > our-</u> <u>services > gynaecology > patient-information</u>

Useful websites

Hydatidiform Mole and Choriocarcinoma UK Information and Support Service

www.hmole-chorio.org.uk/patients_info/introduction-to-molar-pregnancy/

NHS UK www.nhs.uk/conditions/molar-pregnancy

Molar Pregnancy Support www.molarpregnancy.co.uk

Miscarriage Association www.miscarriageassociation.org.uk/information/molar-pregnancy/

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

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