Sheffield Teaching Hospitals NHS
NHS Foundation Trust

Information for patients

Molar pregnancy

Gestational trophoblastic disease



smoke-free hospitals

Weston Park Hospital

Why am I receiving this booklet?

You are receiving this booklet because your gynaecologist has informed us that you have had a molar pregnancy.

We understand this can be an extremely distressing time for you and we have a team of staff here to offer help and support.

It is unlikely that you will have heard of this before as it is such an uncommon condition occurring only once for every 750 live births. The condition can lead to confusion among patients (and doctors!) because of the different strange sounding names used to describe it, for example:

- Hydatidiform mole
- Molar pregnancy
- Partial mole
- Complete mole
- Twin mole
- Invasive mole
- Trophoblastic disease
- Gestational trophoblastic disease (GTD)
- Choriocarcinoma
- Placental Site Trophoblastic Tumour

Another source of confusion is the fact that, after the initial incident which led to diagnosis, most patients feel perfectly well unless they are unfortunate enough to have developed complications. For this reason it may not be clear why we go to such lengths in monitoring and treatment. Of course, when the disease is diagnosed, we try to explain everything we have to do and why.

We hope that this booklet will answer many of your questions but we do realise you may have some questions and concerns or you may just wish to talk to somebody following your molar pregnancy.

In Sheffield at Weston Park Hospital where one of the two molar pregnancy screening and treatment centres in the United Kingdom is based we have a team of people trained and experienced in supporting women following a molar pregnancy.

The team of people includes:

- Professor Rob Coleman, Director of the Treatment Centre
- Mr John Tidy, Consultant gynaecologist,
- Dr Matt Winter, Consultant Oncologist
- Jan Everard, Nurse Consultant
- Annie Hill, Nurse Counsellor
- Jane Cook, Nurse Specialist
- Sarah Gillett, Nurse Specialist

What are Clinical Nurse Specialists and Nurse Counsellors?

They are nurses who are specially trained to give care and support, in this case, to patients following a molar pregnancy.

What do I do if I want this support?

You can get in touch with members of the nursing team, Monday - Friday between 10.00am and 5.00pm.

Telephone: **0114 226 5000** and ask Switchboard to bleep Jane or Sarah on **bleep 3348,** or Annie on **bleep 3292.**

If they are not available please ring the office on:

0114 226 5205.

Alternatively you may prefer to email Annie, Sarah, Jane or Jan at:

Trophoblastic@sth.nhs.uk

If you wish to meet and talk confidentially about your condition, Annie holds a '**Drop In**' clinic once a month. Please ring the office on:

0114 226 5205 and speak to Julie or Tracey who will give you the dates and directions to get here. If the dates are not suitable we will arrange a date to suit.

You may find the patient support website helpful:

www.molarpregnancy.co.uk

This was designed and launched in April 2007 by a Sheffield patient.

There may also be trained staff at your local hospital who can offer support following the loss of your pregnancy.

The miscarriage association can offer support to you and/or your partner over the phone:

Tel. no. **01924 200799**

If English is not your first language and you would like to discuss your molar pregnancy with our nurse specialist, we can arrange an interpreter and talk with you on the telephone.

What is Gestational Trophoblastic Disease?

Gestational Trophoblastic Disease (GTD) is an uncommon complication of any pregnancy. To understand it we look at a normal pregnancy, this consists of two 'parts' developing in the womb: the foetus or developing baby, and the placenta or after-birth.

The placenta has many functions including the feeding of the baby and the removal of its waste products (the placenta is made of millions of cells called trophoblasts). These two parts normally develop together, the end result being a healthy baby and a placenta.

In trophoblastic disease there is an abnormal overgrowth of all or part of the placenta, causing what is called a molar pregnancy or hydatidiform mole. The term seems strange but is similar to that used for a harmless growth on the skin, which is also called a mole.

As with skin moles, a hydatidiform mole is often harmless. However, it can keep growing and, if left untreated, can bury itself into the organs around it, including the uterus (womb) and even spread via the blood to other distant organs including the lungs, liver or brain. It is once it has reached this stage that it can have serious effects. Although a hydatidiform mole is not cancer and rarely becomes cancerous, it can behave in similar ways. Most of our treatment is aimed at stopping the progress of the disease long before any of these things happen.

What are the different types of Gestational Trophoblastic Disease?

Gestational Trophoblastic Disease: sometimes called trophoblastic disease). This is an umbrella term used to cover the range of disease caused by overgrowth of the placenta.

Hydatidiform mole: The commonest kind of trophoblastic disease, where the overgrowth of the placenta is not malignant but it can spread to other parts of the body if not treated. This is divided into:

Partial mole: Where part of an apparently normal placenta overgrows and part develops normally. There may be a developing baby present, but the baby unfortunately cannot survive.

Complete mole: Where the whole placenta is abnormal and usually grows very rapidly. There is unfortunately no developing baby.

Persistent trophoblastic disease: Where part of the mole remains in the body despite initial treatment by the gynaecologist. Even a tiny amount of mole in the body can grow quickly and cause problems, so very close monitoring is very important.

Choriocarcinoma: A very rare form of cancer where the placenta becomes cancerous (malignant.) This can arise from a molar pregnancy or follow an otherwise normal pregnancy or miscarriage. Choriocarcinoma can also spread to other parts of the body.

Placental site trophoblastic tumour:
This is also a very, very rare form of cancer associated with a previous pregnancy.

Who does GTD affect?

GTD only affects women and can occur in anyone of childbearing age (after the start of periods) until the menopause. It is very rare for women to experience this condition after the menopause.

The Sheffield Trophoblastic Screening and Treatment Centre covers a population of over 22 million from the North of England and North Wales. Around 600 women each year are registered in Sheffield following the diagnosis of a molar pregnancy. Charing Cross Hospital in London and Ninewells Hospital in Dundee also monitor women with trophoblastic disease.

How is a molar pregnancy diagnosed?

The diagnosis of a molar pregnancy can be made by the pathologist when he/she looks at the placenta under a microscope. This is done routinely after any miscarriage, termination of pregnancy or ectopic pregnancy. A molar pregnancy may also be suspected for several reasons during an ongoing pregnancy, for example if the womb is larger or smaller than it should be for the stage of the pregnancy, or if you are being sick more than in a normal pregnancy. Complete moles can also have a characteristic appearance on an ultrasound scan, so this and the fact that no developing baby is seen when you have a scan at the ante-natal clinic, can allow the diagnosis to be suspected.

What treatment will I have?

You may have a surgical scrape (or evacuation) of the womb to remove as much of the placenta from your womb as possible. This is a minor operation which is carried out after most miscarriages (it may also be called a D&C or ERPC). In most cases, one or two of these minor operations will be enough to remove the mole permanently. You may have medical management of the pregnancy when drugs are given to remove the placental tissue from the womb, occasionally you may have been left to miscarry the pregnancy yourself.

What happens after my pregnancy has ended?

In a normal pregnancy the placenta makes many hormones to support itself, the baby and the mother. One of these hormones is called human chorionic gonadotrophin (hCG), and in a molar pregnancy, where there is overgrowth of the placenta, there is a large amount of this hormone produced.

This hCG circulates in your blood and is excreted in your urine. This hCG can be easily measured in the laboratory from blood or urine samples. It is helpful in the diagnosis of trophoblastic disease, but even more useful in helping us decide when a patient is cured.

When there is no molar tissue in the body, the level of hCG in the blood and urine is low. When there is a lot of molar tissue in the body, the level is very high. Following the end of a molar pregnancy the levels fall gradually.

How do you measure the hCG in my samples?

Once your diagnosis has been made and you have been registered with our centre which specialises in monitoring women after molar pregnancy you will be sent urine sample bottles in the post, and a stamped, addressed box in which to post them back. We will request a morning urine sample once every two weeks.

In our laboratory the level of hCG in your urine and blood will be measured. All being well, your hCG level will quickly become undetectable and remain so.

The urine tests are important for you because it means we can tell how your disease is progressing without having to call you for frequent examinations.

However, as mentioned earlier, even a tiny amount of mole left

in the body can grow and spread, therefore your disease will be monitored by regular urine samples plus one blood sample approximately 12 weeks after the end of your pregnancy.

How long does monitoring last?

If the hCG result from your urine sample returns to normal within 56 days of the end of your pregnancy, you will be monitored for 6 months from the end of the pregnancy.
If your urine result does not return to normal within that 56 days, monitoring will continue for 6 months from the date of your first normal result. However, if the level stays high or starts to rise, this will be detected at our centre. We will then notify your gynaecologist, who may contact you, or one of our team may contact you by telephone (if no phone number available, by letter.) In around 6% of cases drug treatment is required to remove any remaining disease. If this is the case we must seek consent for any treatment beforehand. Staff will explain the risks, benefits and any alternatives if relevant before they ask for your consent.

If you are unsure about any of the above, please do not hesitate to ask us for more information.

When can I get pregnant again?

As we assess your disease by measuring a hormone normally only seen in pregnancy, if you become pregnant during the course of your follow-up with urine samples, the healthy pregnancy will result in the rapid rise of hCG levels in your urine, which might lead to unnecessary worry and confusion.

Pregnancy following too soon after trophoblastic disease may also increase the risk of recurrence or re-activation of the mole. For all these reasons you are advised to avoid pregnancy for the duration of your sample monitoring.

What method of contraception should I use?

The use of the oral contraceptive pill is not recommended until the hCG levels are normal. We also advise avoiding 'coil' contraception until normal periods have recommenced; condoms are recommended.

Could 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.

How do I get the results of my urine tests?

We will inform you by letter once your test result has returned to normal. On average it takes 8 weeks to return to normal following a pregnancy but can take longer.

You may ring for your results Monday to Friday on:
0114 226 5205 if you wish between 10.00am and 1.00pm.

What happens if I have a new pregnancy?

Please inform our Centre at the end of any future pregnancy as we like to check a urine sample around
6-8 weeks after the end of the pregnancy (including miscarriage) to ensure the hCG hormone has returned to normal.

Summary

- Trophoblastic disease, or hydatidiform mole, is a rare complication of pregnancy, where there is overgrowth of the placenta or afterbirth.
- In the majority of cases the disease is cured by D & C, a minor gynaecological operation or medical management of your miscarriage.
- In around 1 in 15 of patients; where this does not result in a cure, drug treatment is required to eliminate any remaining tissue.
- Progress and cure is measured by hCG, a hormone made by the placenta. hCG appears in the urine and is measured at our specialist centre, by postal samples.
- During the 'monitoring' period, when urine is being tested, if no drug treatment is required to eliminate the disease, you are asked to avoid pregnancy until the hCG levels have been normal for 6 months from either the date of the end of your pregnancy or from the first normal result.
- The oral contraceptive pill should not be taken until the hCG levels have returned to normal, we also advise avoiding 'coil' contraception until normal periods are re-established.
- If left untreated, trophoblastic disease can spread to any part of the body, with serious effects. Monitoring is therefore of vital importance to you.
- After the disease has been cured, expect to conceive a normal, healthy pregnancy if you wish, and remain free of trophoblastic disease for the rest of your life.
- Please do inform us of any change of address or telephone number (including mobiles.)

- As mentioned at the beginning of the booklet we are here to help and answer your questions and concerns. Please do not sit at home and worry - do contact us.
- If English is not your first language please ask someone to contact us, we can arrange an interpreter and speak with you on the telephone.

Your Trophoblastic Screening and Treatment Centre is:

Weston Park Hospital,
Whitham Road, Sheffield S10 2SJ
Tel: **0114 226 5205**
Fax: **0114 226 5511**

Director of Centre: Professor RE Coleman

Consultant Gynaecologist: Mr. JA Tidy

Secretaries: Julie Ford, Tracey Byne Tel: **0114 226 5205**

Centre website: www.chorio.group.shef.ac.uk

Patient Support website: www.molarpregnancy.co.uk

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