Sheffield Teaching Hospitals NHS
NHS Foundation Trust

Molar pregnancy

Gestational trophoblastic disease

Information for patients
Weston Park Hospital

In hospital and in the community
proud to make a difference

Why am I receiving this booklet?

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

Molar pregnacy is such a rare complication of pregnancy and most gynaecologists across the country will only see a very small number of patients with this condition. This is why treatment is provided in specialist centres. Molar pregnancy is one of a number of different conditions that are called Gestational Trophoblastic Disease (GTD). This is why the specialist centres are called GTD centres.

There are two specialist screening and treatment centres in the United Kingdom, one in London and one here in Sheffield. In Sheffield the GTD team care for all women affected by GTD in the north of England and Wales. The Sheffield centre is based in Weston Park Hospital.

This booklet will aim to explain more about molar pregnacy and how it is treated. We understand this can be an extremely distressing time for you and we have a team of staff here to offer help and support. They are called the GTD team.

We hope that this booklet will answer many of your questions but we realise you may have many questions and concerns or you may just wish to talk to somebody following your molar pregnancy. The contact details for staff who provide support and information on molar pregnancy are at the end of this booklet.

What is a molar pregnancy?

A molar pregnancy is one of a number of different conditions that are called Gestational Trophoblastic Disease (GTD). It is a rare condition that can develop during pregnancy.

To help to understand molar pregnancy and GTD it can be helpful to explain the words used.

- Gestational means pregnancy
- Trophoblasts are cells in the placenta

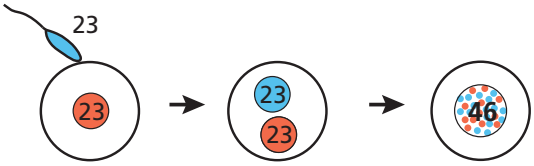
The placenta is the organ that is normally formed as part of a healthy pregnancy. It is attached to the lining of the womb and provides food and oxygen to the baby and produces hormones that help the baby to grow and develop. The placenta is made of millions of cells called trophoblasts. In pregnancy the baby and the placenta normally develop together, resulting in a healthy baby and a placenta.

In trophoblastic disease there is an abnormal overgrowth of all or part of the placenta. This abnormal growth 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 hydaditiform mole is often harmless. It is not a cancer but it can behave in a similar way. If left untreated a hydaditiform mole can keep growing and can grow into the organs that are nearby, such as the uterus (womb). In rare cases they can also spread through the blood to other organs in the body including the lung, liver and brain. If this happens it can have serious effects on the body and health. In some very rare cases it can also become cancerous. Most of our treatment is aimed at stopping the progress of the disease long before any of these things happen.

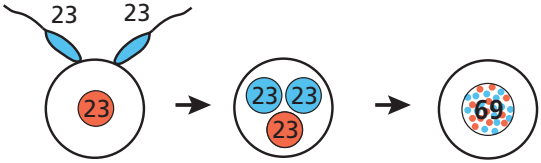
The diagram below shows how an egg normally develops, is fertilised and then implants in the wall of the uterus. In a molar pregnancy at the time of fertilisation there is a problem with either the maternal chromosomes being lost as in a complete mole or there being two sets of chromosomes from the father and one from the mother as in a partial molar pregnancy.

Normal conception



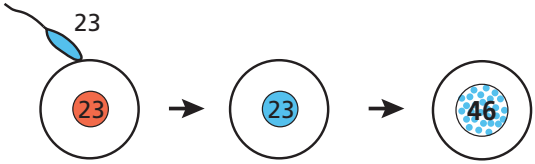
A single sperm with 23 chromosomes fertilises an egg with 23 chromosomes

Partial mole



Two sperm fertilise an egg. This results in a triploid conceptus with 69 chromosomes

Complete mole



The maternal chromosomes are lost

and

The paternal chromosomes double up

This results in a conceptus with 46 chromosomes but all of them are derived from the father

What are the different types of Gestational Trophoblastic Disease?

Gestational Trophoblastic Disease: is an umbrella term used to cover the range of conditions caused by overgrowth of the placenta. The main types are hydatidiform mole, choriocarcinoma and placental site trophoblastic disease.

Hydatidiform mole: This is the commonest kind of trophoblastic disease, where the overgrowth of the placenta is not a cancer growth but it can spread to other parts of the body if it isn't treated. There are two kinds of hydaditiform mole:

> **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 can get GTD?

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.

How is a molar pregnancy diagnosed?

The diagnosis of a molar pregnancy can be made by a specialist doctor, called a pathologist, when they look at a 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 someone is being sick more than in a normal pregnancy.

It can also be picked up on routine ultrasound as complete moles have a characteristic appearance on an ultrasound scan. The scan will also detect if there is no developing baby in the womb.

What treatment will I have?

Treatments to remove the mole include:

- Surgical procedures to remove as much of the placenta from the womb as possible. This can be called a surgical scrape or evacuation, a D&C (dilatation and curettage) or ERPC (evacuation of retained products of conception). In most cases, one or two of these procedures will be enough to remove the mole permanently.
- Medical management when drugs are given to remove the placental tissue from the womb

What happens after my pregnancy has ended?

After your pregnancy has ended we will monitor you to check that the mole has been completely removed. This is done by measuring a hormone called human chorionic gonadotrophin (hCG).

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

hCG circulates in your blood and is excreted in your urine. This amount of hCG can be easily measured in the laboratory from blood or urine samples. 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.

Monitoring the amount of hCG can be helpful in the diagnosis of trophoblastic disease. It is very useful in helping us to follow the effectiveness of treatment.

How do you measure the hCG in my samples?

Once your diagnosis has been made you will be registered with the GTD centre in Sheffield which specialises in monitoring women after molar pregnancy. To monitor the hCG levels we will need a sample of urine once every two weeks. The sample must be taken the first time you pass urine in the morning.

We will send you urine sample bottles in the post, along with a stamped, addressed box so you can return them.

In our laboratory the level of hCG in your urine and blood will be measured. 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.

How long does monitoring last?

All being well your hCG level will reduce until it is no longer present and will remain so. However, as mentioned earlier, even a tiny amount of mole left in the body can grow and spread. This means that your disease will be monitored by regular urine samples. We will also require one blood sample approximately 12 weeks after the end of your pregnancy.

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 56 days, monitoring will continue for 6 months from the date of your first normal result.

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. Alternatively you may be contacted by one of the GTD team. If we have your phone number we will telephone you, otherwise we will contact you by letter.

In around 6% of cases drug treatment is required to remove any remaining disease. If this is the case we will discuss and agree a treatment plan with you.

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.

When can I get pregnant again?

We monitor the progress of molar disease by measuring hCG, a hormone that is only produced during pregnancy. If you become pregnant the level of hCG in your body will automatically rise. If this happens while you are being monitored for your molar pregnancy this can cause some confusion and make it difficult to monitor your molar disease.

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.

Please talk to the GTD team if you have any concerns or questions about this.

What method of contraception should I use?

We have recently reviewed the evidence on taking the pill and new guidelines suggests you may use any contraception you wish.

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.

Should I do anything if I have a new pregnancy?

If you become pregnant in the future, please inform our GTD Centre at the end of the pregnancy. We need 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.

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 the Sheffield GTD centre we have a team of people trained and experienced in supporting women following a molar pregnancy.

The team of people includes:

- Professor John Tidy, Consultant Gynaecologist, Director of the service
- Dr Matt Winter, Consultant Oncologist, Deputy Director of the service
- Professor Michael Wells, Consultant Pathologist
- Dr Branko Perunovic, Consultant Pathologist
- Dr Shahram Abdi, Consultant Radiologist
- Kam Singh, Lead Nurse Specialist
- Annie Hills, Nurse Counsellor
- Jane Ireson and Sarah Gillett, Nurse Specialists
- Julie Ford and Tracey Byne, Secretaries
- Ward 3 doctors and nurses
- Teenage and Young Adult Unit nurses and doctors

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.

Who do I contact if I want support?

You can get in touch with members of the nursing team Monday to Friday from 10.00am to 5.00pm as follows:

Telephone **0114 271 1900** and ask Switchboard to bleep:

Kam on **3349**
Jane or Sarah on **3348**
Annie on bleep **3292**

If they are not available please ring the GTN mobile **07917 041 434** or the office on **0114 226 5205**.

Alternatively you may prefer to email Kam, Annie, Sarah or Jane at **Trophoblastic@sth.nhs.uk**

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.

Drop-in clinic

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.

Other sources of support

www.molarpregnancy.co.uk is a support website you may find helpful. Designed and launched in April 2007 by a Sheffield patient.

Your local hospital may also have trained staff who can offer support following the loss of your pregnancy.

Miscarriage Association can offer telephone support to both you and your partner on **01924 200 799**.

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