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Information for you

Gestational trophoblastic disease

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This information is for you if you have been diagnosed with gestational trophoblastic disease (GTD). It may also be helpful if you are a partner, relative or friend of someone in this situation.

What is GTD?

GTD is a group of conditions that may occur when a pregnancy does not develop properly and includes complete and partial molar pregnancy. Sometimes a molar pregnancy can lead to another form of GTD known as gestational trophoblastic neoplasia (GTN) - see 'What is GTN?' below.

GTD is an uncommon condition. For approximately every 700 pregnancies which end with a live baby, there will be one pregnancy which develops GTD.

What is a molar pregnancy?

Molar pregnancy (also called hydatidiform mole) is the most common type of GTD. In healthy pregnancies, an embryo (baby) develops when a sperm fertilises an egg and the genetic material from each combines to produce a baby which has half of its genes from each parent. A molar pregnancy is abnormal from the very moment of conception as a result of an imbalance in the number of chromosomes supplied from the mother and the father.

There are two types – complete mole and partial mole.

- Complete moles usually occur when a single sperm fertilises an 'empty' egg which has no genetic material inside, and then divides to give the fertilised egg a normal number of chromosomes, all of which have come from the father. Complete moles can also occur when two sperm fertilise an 'empty' egg.

- Partial moles occur when two sperm fertilise a normal egg and the developing pregnancy then has three sets of chromosomes or more. In a partial mole, there are usually some early signs of development of a fetus on ultrasound but it is always abnormal and cannot develop into a baby.

GTD is more likely to develop in women of Asian origin, teenagers and women over 40 years.

When might a molar pregnancy be suspected?

If you have a molar pregnancy you may have irregular or heavy bleeding from the vagina, or excessive morning sickness (hyperemesis). Your uterus (womb) may feel larger than your midwife or doctor would expect in early pregnancy. Less commonly, you may develop raised blood pressure, symptoms of an overactive thyroid gland or abdominal pain because of large ovarian cysts.

If your doctor suspects that you may have a molar pregnancy, you will be referred to an early pregnancy clinic for an ultrasound scan. If you have a complete mole, there will be no baby present inside the pregnancy sac and there may be other signs that suggest the presence of a molar pregnancy. Ultrasound may also help in diagnosing partial moles, but it is not as reliable as in cases of complete moles.

A blood test which measures the amount of the pregnancy hormone human chorionic gonadotrophin (hCG) may also raise the suspicion that you have a molar pregnancy. Usually, the levels of this hormone are much higher than would be expected in a healthy pregnancy.

A molar pregnancy may be found after what is suspected to be a miscarriage.

Can a molar pregnancy survive?

Sadly, as there is no baby present in a complete mole, these pregnancies cannot survive and cannot lead to the birth of a baby. In a partial mole, there may be a fetus visible on scan, but it is not developing properly and also cannot survive.

What happens if a molar pregnancy is suspected?

The preferred treatment for complete molar pregnancy is an operation to take away the pregnancy tissue from your uterus (womb). Medication may be used to soften the cervix (neck of the womb) prior to your operation. You will usually need a general anaesthetic for this type of operation. During the operation, the cervix is stretched slightly and a suction device is used to remove all of the abnormally formed tissue from inside your uterus.

An operation is also the preferred method to treat pregnancies where a partial mole is present. However, sometimes the fetus in a partial molar pregnancy is too large to be removed in this way and you may need to have a miscarriage induced with medication. The doctors looking after you will discuss this with you in detail.

Rarely, a molar pregnancy may develop in one of a set of twins. The outlook for such pregnancies is poor, with only one in four ending with a live baby. Both miscarriage and premature birth are common in these cases. If your doctor is concerned that you have this very rare type of pregnancy, he or she will discuss your case with specialists and you will be referred to a hospital which has expertise in looking after cases such as yours.

Will I need anti-D?

If you have a rhesus negative blood group you should be given medication known as anti-D to prevent your blood system from developing antibodies which may affect the blood cells of any future babies.

What happens after I have my surgery?

The diagnosis of a molar pregnancy can only be suspected prior to your operation. To confirm whether you have had a molar pregnancy or not, the tissue which is removed at operation (known as the products of conception) will need to be examined in the laboratory so that a definite diagnosis can be made.

If you have had a miscarriage, and no fetus was seen on scan before you miscarried, it is recommended that the tissue which is passed is sent for analysis to make sure that you have not had an unsuspected molar pregnancy.

Why do I need to be sure if I have had a molar pregnancy?

In a small number of cases the cells may persist after the pregnancy has been removed. This increases the chances of you needing further treatment. There is also a small risk that if medications are used to induce a miscarriage in molar pregnancies, some of the abnormal cells may pass into your bloodstream.

It is important to be sure if you have had a molar pregnancy or not as there is a small risk that some of the abnormal cells may persist or develop into more severe forms of GTD (see below).

Overall the risk of needing further treatment is about 1 in 7 (15%) after a complete molar pregnancy and 1 in 200 (0.5%) after a partial molar pregnancy. At present

there is no accurate way of predicting immediately after your operation if you will need further treatment.

What follow-up will I have?

In the UK all women who have had a molar pregnancy are asked if their details can be registered with a specialist centre so that treatment can be coordinated and provided by doctors who are experts in this field. These centres are in hospitals in London, Sheffield and Dundee (see contacts below).

After registering with a specialist centre, you will be followed up for at least 6 months. Follow-up involves measuring the pregnancy hormone hCG, either in blood or urine specimens. The specialist centre will post you the kit you need but you will have your blood test done at your GP surgery or local hospital. If you are asked to give a urine specimen, written information will be given on how to do this. If your level of hCG is falling, then the number of abnormal cells in the uterus is also falling and no further treatment is needed.

Length of follow-up will depend on your individual needs. If your levels of hCG return to normal within 56 days of your operation, then you will usually be asked to provide blood and urine samples for 6 months. If your hCG levels take longer to return to normal, you are usually followed up for 6 months from the date when your tests returned to normal. This programme of registration and follow-up has produced high cure rates (98–100%) and very low rates of progression to more serious forms of GTD.

The specialist centre will be able to put you in touch with support groups.

What contraception can I use during follow-up?

You should use barrier methods of contraception such as condoms or diaphragm until your hCG levels are normal.

Once your hCG levels are normal, you may use all types of hormonal contraception including the combined contraceptive pill, progestogen only pill, progestogen injection and progestogen implant. You should not have an intrauterine contraceptive device fitted until your hCG levels have returned to normal as it is more likely to cause a perforation (puncture) in the uterus after a molar pregnancy.

You can discuss with your doctor options for contraception that suit you.

What is GTN?

A molar pregnancy is best thought of as a pre-cancerous illness which can occasionally progress to a cancerous form of GTD known as gestational trophoblastic neoplasia (GTN). GTN is regarded as a rare form of cancer and includes invasive mole, choriocarcinoma, placental site trophoblastic tumour and epithelioid trophoblastic tumour. It has a cure rate of over 99% if it develops after a molar pregnancy.

GTN occurs when some of the molar pregnancy tissue persists in the uterus. It is usually diagnosed if your hCG levels do not return to normal.

GTN can also occur after a miscarriage or a live birth. This is much rarer, happening once for every 50,000 babies born.

If you develop persistent or irregular bleeding after a pregnancy, you may have GTN. You should have a pregnancy test to exclude this and an ultrasound scan is advisable.

What happens if I have GTN?

If you are diagnosed with GTN, you will usually need to have further treatment. This will be organised by the specialist centre that you have been registered with.

If your hCG level is lower than 5000, you may need to have a second operation to empty your uterus (womb). However, further treatment usually involves drugs (chemotherapy). One in seven (15%) women who have a complete mole and 1 in 200 (0.5%) women who have a partial mole will need chemotherapy.

The number and type of drugs that are used depend on your age, type of pregnancy, blood levels of hCG before treatment and how long it is since your pregnancy ended.

The most frequently used chemotherapy (methotrexate) does not cause sickness or hair loss. The side-effects that can occur with methotrexate chemotherapy are generally quite mild producing sore eyes, sore mouth, chest and abdominal discomfort.

Treatment is continued until 6 weeks after your hCG level has returned to normal.

Surgery, such as hysterectomy (removal of the womb) may be required if you have placental site trophoblastic tumour or epithelioid trophoblastic tumour.

Are there any long-term problems?

If you have chemotherapy for GTN, your periods will usually restart 2 to 6 months after the end of chemotherapy and your fertility is usually not affected. However, your menopause is likely to happen slightly earlier than it would have naturally (by 1 to 3 years).

The very few women who need multiple chemotherapy drugs have a slight increased risk of developing other cancers in later life. Your specialist centre will discuss this with you. If your treatment takes less than 6 months to complete, there seems to be no increased risk of these other cancers.

When can I get pregnant again?

Having a molar pregnancy does not affect your chance of having another baby.

You should aim not to get pregnant again until your follow-up programme is complete. For most women this will be approximately 6 months.

If you develop GTN, you should not get pregnant for 12 months after your chemotherapy is complete because up to 3 in 100 women (3%) may experience a return of the GTN. This is detected by a rising hCG level, usually in the first year of follow-up.

Will I have another molar pregnancy?

The risk of a molar pregnancy happening again is 1 in 80. This means that for more than 98 out of 100 women (98%), their next pregnancy will not be a molar pregnancy.

GTD can sometimes recur after a subsequent healthy pregnancy, so you should contact the specialist centre 6 to 8 weeks after all future pregnancies, whatever the outcome, and arrange for a further hCG blood or urine test.