

Gestational trophoblastic neoplasia



Information for patients
Weston Park Hospital



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Introduction

You will receive this booklet when you arrive at Weston Park Hospital for investigations following your molar pregnancy or other type of trophoblastic disease. Gestational trophoblastic disease (GTD) is such a rare complication of pregnancy and most gynaecologists across the country will only see a very small number of patients with GTD, which is why you have been referred to a specialist centre. This booklet will aim to explain more about the GTD team, what GTD is and how it is treated.

GTD team

The GTD team are a group of health professionals trained and experienced in looking after women and their families following a diagnosis of gestational trophoblastic disease. There are two trophoblastic 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.

You will meet members of the GTD team during your time here:

- Professor John Tidy, Consultant Gynaecologist, Director of the service
- Dr Matt Winter, Consultant Medical 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

Who is my key worker?

The key workers in Sheffield are Kam Singh, Jane Ireson and Sarah Gillett. They are clinical nurse specialists in the care of patients with GTD. Clinical nurse specialists are nurses who are specially trained to give individualised care and support, in this case, to patients following a diagnosis of gestational trophoblastic disease.

Your Nurse Counsellor is Annie Hills.

Annie is a nurse who can offer support and information to patients. She is someone to talk to about what has happened and how you are feeling.

What do I do if I want this support?

Please do contact us we are here to help. You can call us Monday to Friday between 9.00am and 5.00pm, or you can email or text, we have a mobile phone that one of us will carry throughout the working week. Our contact details are at the end of this booklet.

When you are in hospital Kam, Jane, Sarah or Annie will visit you daily or you can ask the ward staff to contact one of them to come to the ward and see you.

If English is not your first language one of the staff will arrange an interpreter to explain clearly what will happen and to help you ask any questions you may have.

What is GTD?

Gestational trophoblastic disease 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)
- Gestational trophoblastic neoplasia (GTN)
- Persistent trophoblastic disease
- Choriocarcinoma
- Placental site trophoblastic tumour (PSTT)

Gestational trophoblastic disease (GTD) refers to a group of rare pregnancy related conditions. To help to understand GTD it can be helpful to explain the words used.

- Gestational means pregnancy
- A trophoblast is a placental cell

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 GTD there is an abnormal overgrowth of all or part of the placenta. The trophoblastic cells do not grow as they should, and form a mass of abnormal cells in the uterus (womb). The growth can be either benign

or malignant. Malignant means the abnormal cells can spread to other tissues in the surrounding area and the rest of the body. Benign means it cannot spread. A malignant GTD is more commonly called gestational trophoblastic neoplasia (GTN).

There are three main types of GTD - molar pregnancy, choriocarcinoma and placental site trophoblastic tumour. It is often only possible to diagnose the different types by specialist doctors looking at the abnormal cells under a microscope.

All gestational trophoblastic growths release the pregnancy hormone human chorionic gonadotrophin (hCG). When GTD is first diagnosed, hCG levels can be very high. A high hCG can cause pregnancy related symptoms, such as, nausea and lack of normal periods.

Normal periods do not return in most patients until the pregnancy hormone has almost returned to normal. The high hormone levels can also make you experience mood swings and feel quite tearful.

Molar pregnancy

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 hydatidiform mole:

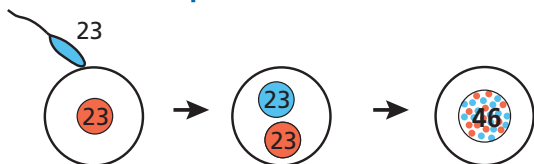
1. Partial mole: Where part of an apparently normal placenta overgrows and part develops normally. There may be a developing baby present, but the baby unfortunately cannot survive.

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

In some very rare cases a mole can coexist with a baby in a twin molar pregnancy.

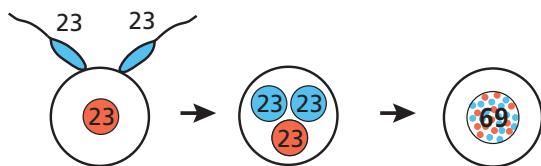
The diagram below shows how an egg normally develops, is fertilised and then implants in the wall of the uterus. In a molar pregnancy at the time of fertilisation there is a problem with either the maternal chromosomes being lost as in a complete mole or there being two sets of chromosomes from the father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

Normal conception



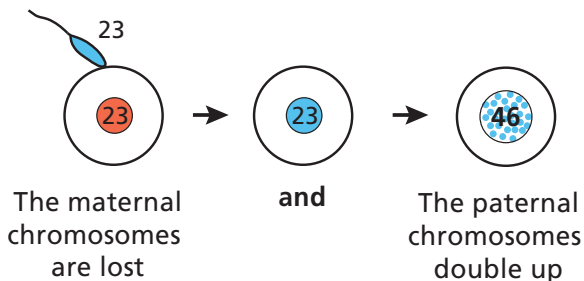
A single sperm with 23 chromosomes fertilises an egg with 23 chromosomes

Partial mole



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

Complete mole



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

In the majority of cases a molar pregnancy is benign and can be successfully treated by surgery. In these cases the hormone levels of hCG return to normal. However, for a small number of patients, part of the mole remains and can grow and spread to other sites in the body, causing a rise in hCG levels. This requires treatment at a specialist centre. If the molar tissue remains and hCG levels are rising, it can also be called an invasive mole or persistent trophoblastic disease.

Choriocarcinoma

Choriocarcinoma is a form of GTN where abnormal placental cells start to grow and spread very rapidly. Choriocarcinoma is more likely to develop after a molar pregnancy. However, it can also occur any time after any type of pregnancy including normal deliveries, miscarriages or terminations.

Placental site trophoblastic tumour

Placental site trophoblastic tumour (PSTT) is the rarest of the GTN group.

What investigations will I need?

The investigations you will need will depend on the type of GTD you have developed and the treatment you will receive. For some patients GTD will not require further treatment and can be monitored by blood samples. Others may need to have further treatment with chemotherapy and will require more frequent monitoring.

You may need any or all of the following investigations. Sometimes patients also need to have other investigations that are not listed here but these will be explained and discussed with you.

Serum hCG: this is a blood test that measures the level of the hormone hCG being produced by the abnormal cells. We will test this level each time before we give you treatment. The level of hCG tells us whether the disease is responding well to treatment or whether a different type of treatment may be needed.

Full blood count: this is a blood test that measures the number of red cells, white cells and platelets in your blood. Chemotherapy can affect the way your body produces blood cells which includes white cells which fight infection and platelets which help your blood to clot. We will check the levels are safe before you have your treatment.

Liver and kidney blood test: chemotherapy can sometimes affect the way the liver and the kidney work. We take blood tests regularly to check they are coping with the treatment.

Chest X-ray: if you have a malignant GTN growth, the abnormal trophoblastic cells can sometimes travel to the lung. This can be monitored with a chest X-ray. The abnormal area of growth should disappear with treatment.

CT scan of your chest: this is performed if your chest X-ray shows areas of abnormal cells in your lung or if the doctor feels there is a clinical reason to do this.

Ultrasound scan of your abdomen: the abdomen is the area in your body below your chest and above your pelvis. An ultrasound of your abdomen may be carried out as sometimes abnormal cells can travel to other parts of your body, although this is rare.

Ultrasound scan of your pelvis: this is normally performed trans-vaginally by placing the ultrasound probe into the vagina. This type of scan is used to help provide clearer pictures of the womb, ovaries and surrounding structures and will show any abnormal tissue still in or near your womb (uterus).

CT or MRI scan of your head: very rarely small amounts of abnormal cells can travel as far as the brain, this is more likely with certain types of GTD. We will carry out a CT or MRI scan in these cases as we need to know if this has happened so we can give the appropriate treatment.

What happens after my investigations?

All scans will be reported by a doctor experienced in looking at scans and X-rays and the results will be passed to the GTD team along with all your blood results.

What will be my treatment plan?

Your scan and blood results will be reviewed by the GTD team and an individual plan of treatment will be discussed with you. You and the team will then decide if you can go home or if it would be advisable for you to stay in hospital.

For some patients GTN can get smaller and disappear on its own without further treatment. In these cases patients can have their condition monitored from home by postal blood samples. However, some patients require further treatment with chemotherapy.

There are a number of different chemotherapy regimens that are used in the treatment of GTN. The consultant looking after you will discuss with you which is the best and most effective treatment according to the results of your investigations.

Once a treatment plan has been agreed you will receive a written treatment plan plus written and verbal information about any drug you may be given. We must seek your consent for any treatment beforehand. Staff will explain the risks, benefits and any alternative treatment, if appropriate, before they ask for your consent. If you are unsure about any aspect of the treatment proposed, please do not hesitate to ask for further information.

The majority of our patients will receive a drug called methotrexate; this is given by intramuscular (into the muscle) injection.

A smaller number of patients require more intensive chemotherapy which is given by the intravenous (into a vein) route. This may be required if there are very high levels of hCG and if the growth has spread to other organs.

The intravenous drugs most commonly used are; etoposide, methotrexate, actinomycin D vincristine, cyclophosphamide. There are also a number of other drugs we use less frequently, such as cisplatin and paclitaxel.

Sometimes we need to change to a different chemotherapy treatment during treatment. This will depend on the response of GTD to treatment and the level of the hCG hormone.

How long does treatment last?

Treatment usually continues until your hCG result has been normal for 6 weeks. Occasionally the consultant caring for you may stop treatment earlier than this if your results do not fall as expected. On average treatment tends to last for around 5-6 months but we are guided by your response to the treatment which we can assess by measuring your hCG. It is impossible to give you an exact completion date.

Tell me about chemotherapy

Once a decision has been made to give chemotherapy you will be allocated a treatment regimen. The most commonly used regimens are either:

1. Intramuscular methotrexate
2. Intravenous etoposide, methotrexate, actinomycin D, cyclophosphamide and vincristine
3. Intravenous carboplatin
4. Intravenous actinomycin D

1. Intra muscular methotrexate

Methotrexate is given by intramuscular injection on alternate days, for 4 doses each cycle. 24 hours after each injection, you will take a tablet called folinic acid, a drug which should prevent any serious effects of methotrexate on normal tissue. It is important you remember to take this tablet at the correct time. Following each treatment cycle, there will be a one week break before starting again.

You are asked to stay in hospital in Sheffield until you have had the first two injections of the first course of methotrexate. This is so we can monitor any side effects you could experience. Occasionally you or the team may feel it wise for you to stay in hospital for the first full course.

Intravenous chemotherapy

Intravenous means into the vein. A small plastic cannula (a thin hollow plastic tube) is placed in the vein to give intravenous chemotherapy. This is removed before you go home. Occasionally patients prefer to have a permanent intravenous line inserted (called a PICC) for the duration of all chemotherapy. Staff experienced in assessing patient's veins will discuss this with you.

2. Intravenous etoposide, methotrexate, actinomycin D, cyclophosphamide, vincristine

Etoposide, Methotrexate and Actinomycin D (Arm A)
Cyclophosphamide and Vincristine (Arm B) are drugs given by the intravenous route as an infusion (a 'drip')

This treatment requires you to stay in hospital for one night every other week. Arm A is given at the first admission with an overnight stay and Arm B at the second admission as a day attendee. These treatments are given alternately on each admission.

3. Intravenous carboplatin

Carboplatin is given intravenously once every three weeks as a day case. We will check your hCG level weekly in between cycles with a blood test which you can send from your local GP or hospital. You will also be given a combination of oral dexamethasone and anti-sickness tablets to take home.

4. Actinomycin D

Actinomycin D is a drug given intravenously once a fortnight as a day case. This drug is given into a fast flowing infusion over approximately 10 to 15 minutes.

You will also be given a combination of oral dexamethasone and anti-sickness tablets to take home.

Occasionally a different regimen of drugs may be given. As with any chemotherapy it is important the drugs are given regularly and each course is completed.

How will I feel during my treatment?

We will give you specific written drug information about possible side effects of any chemotherapy you receive. Each treatment affects patients in different ways. Most people do feel some tiredness during their treatment.

If you are currently employed you may need to think about what you are able to do. Some patients work throughout their treatment apart from the days they need to attend hospital, but others find they feel better by not working.

What side effects am I likely to experience?

This will vary depending upon the type of treatment you receive. The most common chemotherapy regimens can have these side effects:

Intra muscular methotrexate

Those side effects more commonly experienced are:

- Dry, itchy or watery eyes and sore mouth

Side effects less commonly seen are:

- Pleurisy like chest pain
- Abdominal pain
- Heavy vaginal bleeding
- Temporary abnormality of liver and kidney function

Methotrexate should not affect fertility.

Intravenous actinomycin D

Those side effects more commonly experienced are:

- Nausea
- Sore mouth
- Temporary abnormality of liver and kidney function
- Thinning of hair (complete loss of hair is unusual)

Intravenous etoposide, methorexate, actinoymcin D, cyclophosphamide, vincristine

Those side effects more commonly experienced are:

- Lowered resistance to infection
- Nausea
- Sore mouth
- Abdominal pain
- Heavy vaginal bleeding
- Bladder irritation
- Constipation
- Numbness and tingling in hands and feet

Unfortunately all patients receiving this regimen will have a temporary loss of their hair (which may or may not include body hair). Hair does re-grow after the chemotherapy has finished. Do speak with Jane, Sarah or Kam about managing hair loss.

Etoposide, actinomycin D, cyclophosphamide and vincristine is unlikely to have a major affect on fertility other than to bring the menopause forward by a year or two.

Intravenous carboplatin

The side effects more commonly experienced are:

- Lowered resistance to infection
- Bruising and bleeding
- Anaemia
- Feeling sick (nausea) and being sick (vomiting)
- Loss of appetite
- Tiredness (fatigue)

Is there anything I should do while having chemotherapy?

Some suggestions we find may help during chemotherapy:

- Drink 3 litres of fluid a day, this can help to reduce some side effects
- There are certain drugs which you shouldn't take whilst receiving chemotherapy, including some antibiotics, so always inform your doctor what drugs you are taking before they prescribe any new medication.
- Whilst receiving methotrexate, you should not take Ibuprofen (Nurofen) or Aspirin.
- If experiencing vaginal bleeding, use pads rather than tampons (less infection risk).
- Don't sunbathe or use a sunbed as you are more likely to burn. Wear protective cotton clothes and sun-screen lotion when outside during the warmer months.
- Alcohol can affect how chemotherapy is excreted, therefore if you wish to drink alcohol try to limit yourself to 1-2 units a day during your week off treatment and none on the days you are receiving chemotherapy.
- Use condoms for contraception. Occasionally early in your treatment intercourse can cause your vaginal bleeding to increase, if this happens leave it a week to settle and have a word with one of the GTN team. We don't recommend having a coil fitted until normal periods are established after the end of chemotherapy.
- Gentle exercise should be fine once your hormone levels are falling if you are not bleeding heavily and feel well.
- Remember to take your folinic acid tablets.

What if I have any concerns when I get home?

If you feel unwell or have a temperature of 37.5°C or above, contact your key worker or the ward on which you normally receive treatment straight away and ask to speak to the nurse in charge.

If it is Monday to Friday during working hours, try and contact your key worker at Weston Park Hospital with any questions, at other times, speak to the nurse in charge on the ward you normally attend. Don't sit at home worrying! If you are experiencing very heavy vaginal bleeding (heavier than a heavy period) go to your nearest hospital to be assessed and inform them you are receiving treatment at Weston Park Hospital and ask them to contact us

Am I likely to need to change the treatment I am having?

We monitor how well you are responding to the treatment by measuring all your blood tests at the beginning of each new course of treatment and speaking with you. If there are concerns that either the treatment does not suit you or that you are not responding as well as we would like, then we may change to a different chemotherapy.

Around 30% of patients will need to change from one treatment to another at some stage.

Occasionally there can be a role for surgery in the treatment of GTN.

Do I have to come to Sheffield for all my treatment?

Initially all your treatment will be given in Sheffield. This is because GTN is a rare condition and you will need the help and advice of experienced staff. If receiving intravenous chemotherapy, all treatment will be given in Sheffield.

If receiving intramuscular methotrexate we can usually arrange for some of the injections to be given at a hospital closer to you if they are trained in administering chemotherapy.

What if I have money worries?

Speak with your key worker who will advise on any help we can offer, you may be entitled to help with transport to and from the hospital.

What happens when my treatment is finished?

You will be given a written discharge plan when you finish treatment and be offered a clinic appointment to see Dr Winter around 6 weeks post treatment. Initially we will ask you to send us a blood sample in the post once a week so we can ensure your hormone level remains low. Monitoring continues after that with less frequent blood samples and then just urine samples.

We do monitor all our patients for life after they have received treatment in Sheffield.

When will my periods return?

You will probably not have normal periods during your treatment. Some women have a small amount of vaginal bleeding, with period-like discomfort, backache, abdominal (tummy) pains and distention (bloating). Irregular vaginal bleeding can also be caused at this time by the molar tissue (placenta) breaking down, as the treatment starts to work. After treatment, your periods will return to normal, although we are not able to say exactly when this will happen.

Please do not use tampons during treatment or for 6 weeks afterwards due to the risk of infection. However, if you experience a high temperature or fever, or notice any swelling or soreness it is important to seek medical advice as you may have an infection. If this happens while you are on treatment contact your key worker or the ward on which you normally receive treatment straight away. If you ring the ward ask to speak to the nurse in charge. If you have finished all of your planned chemotherapy treatment please contact your GP or the ward.

Will I be able to have another baby after my treatment has finished?

The majority of patients who try for another pregnancy after treatment are successful.

When can I plan a new pregnancy?

We recommend waiting 12 months from the end of treatment before trying again for a baby. For some women, this can seem a very long time to wait. For others, pregnancy is the last thing on their minds. It is worth noting that how you feel now may well change. Our advice to wait is due to the small risk of relapse (3% overall), most of which occur within the first year. It is important to know that if you are pregnant, your hCG will increase quickly with the pregnancy and we will not be able to detect a relapse of the disease.

Am I likely to develop a mole again?

Following one molar pregnancy you are at an increased risk of having a further molar pregnancy but the majority of patients who try for a baby do not have a further molar pregnancy.

Is there a molar pregnancy charity?

Yes, Sheffield has a charity dedicated to research into gestational trophoblastic disease, called Jean's Trust. If you would like to hear more about this charity please do ask one of us, or look at the following website: www.chorio.group.shef.ac.uk/jean.html

Contact details for the GTN team

We do appreciate the impact on family life when attending Sheffield regularly throughout your treatment, please do speak with Kam, Jane, Sarah, or Annie about particular concerns. You can contact them as follows:

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

- Kam on **3349** (Mon - Fri, 9.00am - 5.00pm)
- Jane or Sarah on **3348** (Mon, Tues, Thurs, Fri, 9.00am - 5.00pm)
- Annie on **3292** (Mon, Wed, Thurs, 10.00am - 4.00pm)

If they are not available please ring the 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 your call is urgent and Kam, Jane, Sarah or Annie are not available, please ring the ward you are normally treated on and they will arrange for the appropriate person to speak with you.

- Ward 3 **0114 226 5304/5**
- Teenage and Young Adult Unit **0114 226 5728 / 9**

Support from an interpreter

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.

Treatment centre address

Weston Park Hospital
Whitham Road
Sheffield
S10 2SJ

Useful contacts for further information and support

www.molarpregnancy.co.uk

This is a support website for patients with trophoblastic disease which was designed and launched by a Sheffield patient in April 2007.

- **www.chorio.group.shef.ac.uk**

This is the Sheffield group website where further information and contacts can be found.

- **www.macmillan.org.uk**

Macmillan Support are the UK's leading cancer information site providing up to date practical advice and support including information about different drugs, coping with side effects, financial issues and much more. They can also be contacted by phone on 0808 808 00 00.



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