

Cancer Services

Gestational Trophoblastic disease (GTD)

Information for patients, relatives and carers

Introduction

This booklet is designed to give you additional information about Gestational Trophoblastic Disease (GTD) and the treatments that are often given. We hope it will answer some of the questions that you or those who care for you may have at this time. This booklet is not meant to replace the discussion between you and your medical team. Instead, it aims to help you understand more about what has been discussed.

What is trophoblastic disease?

GTD is a spectrum of illnesses that are rare, usually curable but not always well understood. The types of trophoblast disease range from the usually benign partial molar pregnancy through complete molar pregnancy and invasive mole to malignant choriocarcinoma and the rare placental site and epithelioid trophoblast tumours. More recently, a new member of this group has been discovered called an Atypical Placental Site Nodule (APSN). All of these illnesses share the characteristic that they arise from the placenta, which is part of a pregnancy and are described below. This does not include APSN, which we detail in a separate booklet.

What is a molar pregnancy?

Molar pregnancy is one of a group of conditions known as gestational trophoblastic disease (GTD). It is also called a hydatidiform mole. There are different types of molar pregnancy.

Complete molar pregnancy

A complete molar pregnancy happens when a sperm fertilises an empty egg that contains no chromosomes or genetic material (DNA) from the woman.

In a complete molar pregnancy, no parts of a baby (foetal tissue) form. There is only molar tissue in the womb.

You have surgery or drug treatment to remove the molar tissue. Afterwards, any residual molar tissue usually dies out. However, in around 10-15 out of 100 women (around 10-15%) some molar tissue remains in the deeper tissues of the womb or other parts of the body. This is called an invasive mole. An invasive mole is cancerous and is usually treated with chemotherapy.

Partial molar pregnancy

A partial molar pregnancy forms when two sperm fertilise the egg at the same time. There is one set of female chromosomes and two sets of male chromosomes.

There may be some foetal tissue within the molar tissue so it may look like there is a foetus on an ultrasound scan, but sadly, the foetal tissue cannot develop into a healthy baby due to the chromosome abnormality.

Most women with a partial molar pregnancy do not need to have any further treatment after the initial removal of molar tissue from the womb. However, around 1 in 100 women (around 1%) have some remaining abnormal cells in the deeper tissues of the womb or other parts of the body. This is called an invasive mole or persistent trophoblastic disease (PTD).

Invasive mole

Invasive mole is most commonly found in the womb, but can spread to other areas of the body and might cause symptoms there.

Even a very small amount of molar tissue anywhere in the body can grow and cause problems, but it has a cure rate of virtually 100%.

Choriocarcinoma

A choriocarcinoma is a cancer that happens when cells in the placenta that were part of a molar pregnancy or any other type of pregnancy (full term, miscarriage or ectopic) become cancerous.

Choriocarcinoma only happens in about one in every 50,000 pregnancies.

A choriocarcinoma can develop some months or even years after pregnancy. It can be difficult to diagnose because it is so rare. It can grow quickly and might cause symptoms within a short period of time and spread to other parts of the body, but it is usually cured by chemotherapy treatment. We aim to start treatments for this as soon as we can.

Placental Site and Epithelioid Trophoblastic tumours

These are extremely rare tumours comprising 0.2% of all GTD cases. At Charing Cross we have now seen over 160 cases and have the world's largest experience. If these cancers are just in the uterus, then treatment is normally a hysterectomy (surgical removal of the womb), possibly followed by chemotherapy with or without immunotherapy.

However, if the disease has spread to other organs (known as 'secondary spread'), treatment is usually chemotherapy to begin with followed by immunotherapy and, in some cases, surgery to remove any tumours left after treatment.

Do I have cancer?

The World Health Organisation (WHO) classifies partial and complete hydatidiform moles as 'pre-cancerous' tissue. It becomes classed as a cancerous condition if it develops into a persistent or invasive mole. This usually occurs in around 10-15% of cases for complete moles and around 1% for partial moles.

Choriocarcinoma placental site and epithelioid trophoblastic tumours are classified as cancers from the point of diagnosis

Am I going to be cured?

The cure rate for GTD cancers is almost 100 percent, even if the first treatment is not successful. The overall cure rate for Choriocarcinoma is around 98% and for Placental site and epithelioid tumours is around 85%. Screening within the service continues after any treatment is completed to ensure any signs of the cancer returning are detected early.

Why do I have to go Charing Cross Hospital for my treatment?

As trophoblastic disease is rare, you have been referred to a specialist centre that has the experience, knowledge and expertise in treating and managing this disease.

There are only two treatment centres in the UK – Charing Cross Hospital in London and Weston Park Hospital in Sheffield. There is a follow-up centre at Ninewells Hospital in Dundee, Scotland.

Diagnosis and treatment

You will already have had a diagnosis of a molar pregnancy or other form of gestational trophoblastic disease and will likely have been undertaking regular screening when you read this booklet. The initial treatment for molar pregnancies is usually an operation called a dilatation and curettage ('D&C'). This operation is normally all that is needed to treat hydatidiform moles. However, to make sure that there is no abnormal tissue remaining, we will have been measuring your hCG levels every two weeks.

You will likely have had several consecutive hCG rises or a plateau in hCG levels where they have not returned to a normal range, which is why you have been called to an appointment at Charing Cross. You will now be given more treatment, explained below, which normally results in a complete cure.

Patients with choriocarcinoma, placental site trophoblastic tumours or epithelioid trophoblastic tumours need careful investigations with CT and MRI Imaging and genetic testing to determine which previous pregnancy this diagnosis is associated with. Treatment is determined and adapted according to the results obtained.

How your clinical nurse specialist (CNS) can help you during your treatment

Your CNS is an experienced specially trained nurse who works with the other members of the team to provide medical and psychological care to people with trophoblastic disease and their families.

Your CNS is able to assist in co-ordinating your care during your treatment. They are able to clarify any information, discuss matters important to you, provide emotional support and refer or signpost you to other professionals if required. It is very important that you are able to have your questions answered and concerns discussed. Your CNS will make every effort to ensure this happens.

You will be given a telephone number to contact your CNS (via the Macmillan Navigators) so that you will be able to get in touch with the team if you have any worries or need further information when you are at home.

Things to avoid during and after chemotherapy treatment

You should avoid being out in the sun as much as possible and avoid using sun beds as your skin may be more sensitive than usual. Use a total sun block (factor 50 or above) on exposed areas but ideally wear a hat and keep your body covered in the sun where possible. You should continue to do this for one year after chemotherapy treatment has ended.

As your resistance to infectious illnesses may be lower than usual, try to avoid obvious sources of infections, such as crowded places, swimming pools and people with coughs and colds. If you need dental work, please speak to your consultant or CNS.

Sex and contraception

If you wish, you can have sex following removal of a molar pregnancy during treatment, provided it does not cause or aggravate any bleeding. However, it is very important that you do not become pregnant. This is because we will not be able to tell whether the rise in hCG is due to the existing GTD or a new pregnancy.

The only contraception you should use during this time is a condom together with a spermicidal pessary or foam (available from chemists and family planning clinics). No other form of contraception is suitable during this time.

Once your treatment is finished, you can use any method of contraception you wish (including the pill), but you should wait at least six weeks before an IUD (coil) is fitted.

Going through treatment may affect the way you feel about yourself and your confidence, this is very normal. If you would like discuss any concerns, please speak with your CNS. Counselling is also available if required.

How do we decide what treatment is needed for Invasive Mole or Choriocarcinoma

We will use the results of your latest hCG and imaging tests along with some other simple facts to work out whether your tumour is likely to respond well to one chemotherapy drug alone or if you need to start a multi drug chemotherapy regime. This is done using a scoring system which your clinical team can explain to you.

Do I need to stay in hospital for my treatment?

Your doctor will discuss with you what treatment is recommended. See more information on these treatments below.

You will be asked to stay in hospital for at least one week as we start the treatment. The inpatient stay is because there is a risk of heavy bleeding once the treatment has started. It is also important for us to observe how your body responds and reacts to the treatment.

During this stay in hospital, we will ask you not to leave the hospital, but you will be free to walk around the hospital itself, as long as you are feeling well and are not experiencing heavy bleeding. You are welcome to have visitors, watch films, read books or magazines, or use your laptop if you have one.

You will likely meet other women with the same or a similar diagnosis on your ward, and you may find it comforting to talk to them about how you are feeling or about your worries. It is normal to feel upset and tearful at times throughout your treatment due to your raised hCG levels, reactions to your diagnosis, to the chemotherapy and also to the loss of pregnancy. Emotions can vary from day to day and between individuals. Please see information at the end of this leaflet for details of additional support available.

Single drug treatment

A chemotherapy drug called methotrexate, which causes the trophoblastic cells to die away is usually given as the first treatment. The drug is given as an injection into your muscle in your bottom once every two days. On the days that you do not have the injection, you'll be given a folinic acid tablet. This will help protect your normal body tissues from the effects of methotrexate while it targets the trophoblastic cells.

It is very important that you take this tablet 30 hours after your methotrexate injection (unless directed otherwise). In one cycle of treatment, you will have four injections and four folinic acid tablets, making a total of eight days. After each 8-day cycle of treatment, you will have a six-day rest before starting the next course.

Treatment will continue until the hCG levels fall to normal (less than 5) and then a further 3 cycles are given to ensure that the treatment has been successful. Roughly, two thirds of patients are cured with this treatment. There is a small proportion of patients who will need to switch treatment if the hCG levels do not fall appropriately on the methotrexate injections.

Are there any side effects?

Yes, but these are usually minimal. They can include some of the side effects described below. These side effects are not necessarily going to affect you, but it is important that you are aware

of what could happen. Please tell the nurse or doctor if you experience any of the below symptoms so that problems can be dealt with promptly. Please remember you will remain fertile, and you will not lose your hair on the methotrexate treatment

Sore mouth

Please drink plenty of fluid per day. This will help flush the methotrexate through your kidneys, which will prevent or greatly reduce the risk of getting a sore mouth. Please use the mouthwash provided during the 8 days of treatment and longer if you need to.

Sore eyes

Your eyes may feel 'gritty'. We will provide eye drops to relieve this, please use these as necessary. Please wear glasses rather than contact lenses during this time.

Nausea

You may feel sick. We can give you some anti-sickness pills (known as 'anti-emetics') if needed.

Abdominal (tummy) and chest pains

You may experience period like pains or sharp pains in the tummy or chest whilst on treatment.

This may be relieved by taking paracetamol.

Changes to blood counts

As with all chemotherapy, your blood count can fall, but the risk of this is very low for this type of treatment. This is called myelosuppression.

Your blood count (the number of red blood cells, white blood cells, and platelets in your blood) will be checked before the start of each treatment cycle.

Personal Hygiene

Brush your teeth with a soft toothbrush three times a day and floss regularly. Please rinse your mouth after eating to help clear your mouth of any food debris, which could cause irritation. Please do not use tampons during your treatment or for six weeks afterwards, due to the risk of infection. If you experience a high temperature or fever, or notice any swelling or soreness around the vagina, please contact the clinical team or seek urgent medical advice.

Alternative Single Drug Treatment (Actinomycin D)

On occasion, women who have received initial Methotrexate treatment need to change to a different treatment regime. This can occur in approximately one third of patients. If your hCG levels are 10,000 or below, you will be given Actinomycin D. This is a drug that is given over around 15 minutes every 14 days until your hCG level is normal, followed by a further three cycles to complete the treatment. If your HCG levels are above 10,000 you will require a different more intensive treatment.

Are there any side effects with Actinomycin D?

These can vary from patient to patient and may include some of the side effects below. These side effects are not necessarily going to affect you, but it is important that you are aware of what could happen. Please tell the clinical team if you experience any of the below symptoms so that we can help you feel better.

Sore mouth

Please drink plenty of fluid per day. This will help flush the drug through your kidneys, which will prevent or greatly reduce the risk of getting a sore mouth. Please use the mouthwash provided during the 8 days of treatment and longer if you need to.

Nausea and vomiting

There is an increased risk of feeling sick, compared to the methotrexate treatment. You will be advised to take anti-sickness medication every day with the chemotherapy, and for the days after if required. This usually consists of two drugs called Ondansetron and Domperidone.

Hair Thinning

Most people who have Actinomycin experience hair thinning which starts a few weeks after treatment begins. This is temporary.

Changes to blood counts

As with all chemotherapy, your blood count can fall, but the risk of this is very low for this type of treatment. This is called myelosuppression.

Your blood count (the number of red blood cells, white blood cells, and platelets in your blood) will be checked before the start of each treatment cycle.

Fatigue (extreme tiredness)

This can vary from person to person. There are some simple ways to manage fatigue on a day-to-day basis and your nurse specialist will be happy to advise you.

Personal Hygiene

Brush your teeth with a soft toothbrush three times a day and floss regularly. Please rinse your mouth after eating to help clear your mouth of any food debris, which could cause irritation. Please do not use tampons during your treatment or for six weeks afterwards, due to the risk of infection. If you experience a high temperature or fever, or notice any swelling or soreness around the vagina, please contact the clinical team or seek urgent medical advice.

Multi Drug Chemotherapy

This treatment may be given to women with choriocarcinoma or those with particularly high levels of hCG and/ or if the Hydatidiform mole has spread to other organs, or has not responded to previous single drug chemotherapy.

The standard treatment is a combination of chemotherapy drugs. The regime is known as 'EMA/CO'. All the drugs are given intravenously (via a needle in one of your veins) by drip.

One week you will have the EMA treatment and the next you will have the CO treatment, both detailed below. Treatment will continue until the hCG level falls to normal and then a further 3 cycles of treatment to ensure that it has been successful.

Your blood count (the number of red blood cells, white blood cells, and platelets in your blood) will be checked before the start of each treatment and you will only be given any treatment if your blood count is suitable and safe for treatment.

Once you have been established on treatment and things are stable, it may be possible to have part of this treatment given closer to home. Treatment will continue until the HCG has been normal for 6-8 weeks as advised by your medical team.

Week 1 – EMA (Etoposide, Methotrexate and Actinomycin D). You will need to stay overnight in Charing Cross Hospital for this treatment as the drugs are given over 2 days.

Day 1

You will be given Actinomycin D, this takes around five to ten minutes.

Etoposide is given, which takes around one hour

You will be given methotrexate over approximately 12 hours. You will also be given folic acid tablets to take at set intervals (as directed).

Day 2

You will be given Etoposide and Actinomycin D on the ward prior to discharge home. Day 2 will be given until your tumour markers normalise (HCG less than 5)

Week 2 – CO (Cyclophosphamide and Vincristine)

You will be given vincristine, which takes around 10 minutes, and cyclophosphamide, which will take around one hour. This is given as an outpatient and can be given in your local hospital if they agree.

Are there any side effects associated with EMA/CO?

Side effects vary with each individual. They are listed below so that you are aware of what may happen:

Hair loss (Temporary)

Nausea (feeling sick) and vomiting (being sick)

Myelosuppression (a reduction in blood count)

Fatigue (extreme tiredness)

Mouth ulcers

Loss of appetite

Sore eyes

Tingling in the hands and feet

Temporary Menopause

Personal Hygiene

Brush your teeth with a soft toothbrush three times a day and floss regularly. Please rinse your mouth after eating to help clear your mouth of any food debris, which could cause irritation. Please do not use tampons during your treatment or for six weeks afterwards, due to the risk of infection. If you experience a high temperature or fever, or notice any swelling or soreness around the vagina, please contact the clinical team or seek urgent medical advice.

Your clinical team and other nursing staff will be able to discuss all of these side effects with you.

Complementary therapies

Complementary therapies including aromatherapy, massage and a relaxation group are available via the Maggie's Centre in the grounds of Charing Cross Hospital. Nursing staff can give you further details.

What happens when I am discharged?

You will require twice weekly blood tests and further cycles of treatment as directed. The blood samples can be taken at your local hospital and will be done twice a week until your hCG is normal, then once a week after that. This is necessary for all patients.

If you are not sure when/where these are done, please ask your CNS. The CNS team can detail your individual treatment schedule for you.

You need to continue weekly hCG monitoring once your chemotherapy is completed until you seen in clinic post treatment at around 6 weeks.

When can I try to get pregnant again?

You should wait for at least one year after the end of your treatment before becoming pregnant again. This is so we can monitor your hCG levels to make sure we have completely treated your disease.

Most women trying for a baby after treatment have gone on to have normal pregnancies and healthy babies.

What is the risk of having another hydatidiform mole?

Although we cannot guarantee that you will not have another hydatidiform mole or choriocarcinoma, we are able to reassure you that it is very rare for this to happen. The risk of having a second hydatidiform mole is less than one per cent. A previous choriocarcinoma does not increase your risk of a further choriocarcinoma.

Further sources of support and information

Macmillan cancer navigator service at Imperial College Healthcare NHS Trust

This is a single point of contact for cancer patients at Imperial College Healthcare NHS Trust, and their family, friends and carers. The service is here to help you to navigate your care and resolve queries that you may have. Our Navigators can access information about your appointments, connect you to appropriate services and signpost you on to further support. They can also book you in for a telephone call back from your Clinical Nurse Specialist (CNS) if you have a question that needs clinical input.

The service is open Monday to Friday 08:30 to 16.30 excluding bank holidays. (The service is closed for training between 14.00- 14.45 on Thursdays.)

Call: **020 3313 0303**

Macmillan cancer information and support service at Imperial College Healthcare NHS Trust

The Macmillan cancer information and support service offers free support and information to anyone affected by cancer, including family and loved ones. The service has physical centres at Charing Cross and Hammersmith Hospitals, and also offers virtual and telephone support. When you call or visit you can speak to one of the Macmillan cancer team one-on-one about whatever matters most to you. You can sign up to a range of weekly virtual groups that provide the opportunity to connect with other people with cancer in a relaxed environment. You can also speak to our Macmillan welfare and benefits adviser, who can offer patients of the Trust tailored advice on additional financial support.

The service is open Monday-Thursday (excluding bank holidays), with various drop-ins available within our physical centres. For more information please call us on **020 3313 5170** or email [**imperial.macmillansupportservice@nhs.net**](mailto:imperial.macmillansupportservice@nhs.net)

Maggie's West London

Maggie's is a cancer charity that provides the emotional, practical and social support to people with cancer and their family and friends.

The centre offers a calming and beautiful space, a professional team of support staff, and the opportunity to talk and share with a community of people who have been through cancer too.

Maggie's centres are warm, friendly and informal places full of light and open space, with a big kitchen table at the heart of the building. Maggie's West London is located in the grounds of Charing Cross Hospital but is independent of our hospital.

The centre is open Monday to Friday, 09.00-17.00. For more information please call **020 7386 1750**.

Macmillan Support Line

The Macmillan Support Line offers confidential support to people living with cancer and their loved ones. This support line is a national line provided by Macmillan and is independent of our hospital.

The Support Line is open every day, 08:00 to 20:00. Please call: **0808 808 000** or visit www.macmillan.org.uk

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

Wi-fi is available at our Trust. For more information visit our website: www.imperial.nhs.uk

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