Trophoblastic disease (hydatidiform moles and choriocarcinoma)

Information for patients, relatives and carers

Introduction

This booklet is designed to give you information about trophoblastic disease. 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, but aims to help you understand more about what is discussed.

What is trophoblastic disease?

Trophoblastic disease (sometimes called gestational trophoblastic disease) is a general term used to cover several diseases which occur in pregnancy. There are several types of trophoblastic disease such as hydatidiform mole, choriocarcinoma and placental site tumour.
Hydatidiform mole (also called molar pregnancy)
This happens in approximately one in every 500 known pregnancies and is caused by abnormal fertilisation of the egg. In a normal pregnancy, the placenta (which is made up of millions of cells known as trophoblastic cells), feeds the growing baby and removes its waste products.

In trophoblastic disease, the trophoblastic cells are abnormal and cause the placenta to overgrow. This is known as a ‘hydatidiform mole’ or ‘molar pregnancy’.

In about one in 10 cases of hydatidiform moles, it keeps growing and buries itself into the lining of the uterus (womb) and can even spread via the bloodstream to other organs.

There are a number of different types of hydatidiform moles, described below.

**Partial mole**
This is where only part of the placenta is growing abnormally. There may be some foetal development, but the foetus will never survive and will miscarry early in the pregnancy.

**Complete mole**
This is where the whole placenta is abnormal and usually grows very rapidly. There is no foetus present in these pregnancies.

**Persistent or invasive mole**
In some cases of partial and complete moles, the trophoblastic cells may burrow deeply into the lining of the womb and they can sometimes spread to other organs.

**Choriocarcinoma**
This is where the placenta, made up of trophoblastic cells, becomes
malignant (cancerous) and may spread throughout the body. It can arise from a hydatidiform mole, or following a normal pregnancy, a miscarriage, an ectopic pregnancy, a stillbirth or a termination of pregnancy. It occurs in approximately one in 50,000 normal pregnancies.

**Placental site tumour**
This is an extremely rare tumour. In fact, at Charing Cross Hospital, there have only ever been 92 cases, up to 2014. If the disease is just in the uterus, then treatment is normally a hysterectomy (surgical removal of the womb), possibly followed by chemotherapy. However, if the disease has spread to other organs (known as ‘secondary spread’), treatment is usually chemotherapy to begin with and, in some cases, surgery as well.

**Have I got 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.

Choriocarcinoma and placental site tumour are classified as cancers from the point of diagnosis.

**Am I going to be cured?**

Almost certainly. For women with all types of hydatidiform moles, this increases to almost 100 per cent. The overall rate of survival for choriocarcinoma and placental site tumour is over 90 per cent.
Why do I have to go Charing Cross Hospital for my treatment?

As trophoblastic disease is rare, you are being referred to a specialist centre that has 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 have been registered at Charing Cross Hospital, your regional centre, which specialises in the monitoring of trophoblastic disease.

In a normal pregnancy, the placenta produces a hormone called hCG (human chorionic gonadatrophin) to support the growth of a foetus. In the case of a hydatidiform mole, the overgrowth of the abnormal placenta produces a large amount of hCG. This can be measured in the blood and urine.

A hydatidiform mole is usually identified by ultrasound. It is treated by a minor operation called a dilatation and curettage (‘D&C’). This is when the placenta is surgically removed from your uterus (womb).

This operation is usually carried out after miscarriages. This is normally all that is required for treatment of hydatidiform moles. However, to make sure that there is no abnormal tissue remaining, we will measure your hCG levels every two weeks by testing your blood until your hCG reaches normal levels.
In about 10 per cent of women who have a hydatidiform mole, it continues to grow despite the surgery. This can be detected by your hCG levels which may stop falling, stay at the same level, or rise. Further treatment will then be needed; this is explained in more detail below. This normally results in a complete cure.

What happens if I require more treatment?

Firstly, you will be admitted to Charing Cross Hospital to have a number of routine tests. These tests will include a pelvic ultrasound scan, chest x-ray and blood tests, done both to monitor the disease and to assist the doctors in determining the type of further treatment required. Chemotherapy drugs are used in this further treatment and your doctor will advise you whether ‘low-risk’ or ‘high-risk’ chemotherapy treatment is needed.

You will stay for one to three weeks depending on your hCG levels. You may find it distressing to stay so long in hospital, but it is necessary, as there is a risk of heavy bleeding when treatment is started. It is also important to observe how your body responds and reacts to the treatment.

During this longer stay in hospital, we will ask you not to leave the premises but you will be free to walk around the hospital itself. Although this is not ideal, it is a precautionary measure as you are at risk of heavy bleeding. You may find your stay in hospital boring at times, especially as most of the time you will feel fairly well.

However, you will meet other women with the same or a similar disease and you may find it comforting to share your concerns with them. It is normal to feel upset and tearful at times throughout your treatment due to raised hCG levels, reactions to your diagnosis, to
the chemotherapy and also to the loss of a baby. Emotions can vary from day to day and between individuals.

Low-risk treatment

A chemotherapy drug called methotrexate is used in this type of treatment. This causes the trophoblastic cells to die away. The drug is given as an injection in the bottom on alternate days.

You will also be given a folinic acid tablet to take on the days between the injections. This is a ‘rescue’ medication to help protect the normal body tissues from the effect of methotrexate. It is very important that you take this tablet 30 hours after your methotrexate injection. In one cycle of treatment, you will have four injections and four folinic acid tablets, making a total of eight days. After each cycle of treatment, you will have a six-day rest before starting the next course.

Are there any side effects associated with low-risk treatment?

Yes, but these are usually minimal. They can include some of the side effects described below.

Sore mouth

Please drink three litres of fluid (such as water, tea or fruit juice) per day. Brush your teeth with a soft toothbrush three times a day and floss regularly. This will help flush the methotrexate through your kidneys, which will prevent or greatly reduce the risk of getting a sore mouth. We will also give you some Corsodyl mouthwash to use after every meal and before you go to bed.
Sore eyes
Your eyes may feel ‘gritty’. We can provide eye drops to relieve this. You should avoid wearing contact lenses during this time.

Nausea
It is possible you may feel sick. We can give you some anti-sickness pills (known as ‘anti-emetics’) if needed.

Abdominal (tummy) pain
This may feel like period pain. The doctor on the ward will prescribe painkillers to help with this.

Chest pain
Some women experience pain in the chest, particularly on deep breathing. This can be relieved by painkillers and will resolve once all the treatment is finished.

Myelosuppression
As with all chemotherapy, there is a tendency for the blood count to fall. Although with this type of treatment the risk is minimal, it is routine to check the full blood count before each course of treatment.

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 above symptoms so that problems can be dealt with promptly. Please remember you will remain fertile and you will not lose your hair on the low-risk treatment.

High-risk treatment
High-risk treatment may be given to women with particularly high levels of hCG and/or secondary spread to other organs.
The standard treatment consists of 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.

**Week 1 – EMA**

- Actinomycin D is given via a fast-running infusion of normal saline (water and salts solution). This takes approximately five to ten minutes.

- Etoposide is given via a 500 ml bag of normal saline infusion. This takes one hour.

- Methotrexate is given via a one-litre bag of normal saline infusion. This takes approximately 12 hours. We will give you a short course of folinic acid tablets to take 24 hours from the start of the methotrexate.

You will need to stay overnight in Charing Cross Hospital for this treatment programme.

**Week 2 – CO**

- Vincristine is given in the same way as the Actinomycin D - via a fast-running infusion of normal saline. This takes about 10 minutes.

- Cyclophosphamide is given via a 500 ml bag of normal saline infusion. This takes one hour.

The EMA and CO chemotherapy regime alternate at weekly intervals. One week you will have EMA and the next, CO. Please note that your blood count will be checked before the start of each
treatment and chemotherapy will only be given if your blood count is normal.

The EMA treatment will carry on at Charing Cross Hospital. Once you are well enough, you will be able to have the CO treatment at your local hospital as an outpatient.

Are there any side effects associated with high-risk treatment?

It is important to realise that side effects vary with each individual. They are listed below so that you are aware of what may happen:

- hair loss (this is temporary)
- nausea (feeling sick) and vomiting (being sick)
- myelosuppression (fall in blood count)
- fatigue (extreme tiredness)
- mouth ulcers
- loss of appetite

Your clinical nurse specialist (CNS)/key worker and other nursing staff will discuss all of these side effects with you. We will also advise you to read the chemotherapy booklet, which is available from the ward staff.

Second-line treatment

On occasion women who have received low-risk treatment need to change to a stronger treatment regime because the hCG levels get
stuck. This is described as ‘resistance’ and can occur in approximately one in four patients who are receiving low-risk treatment. If your hCG levels are at 1000 or below, the appropriate second-line treatment is called Actinomycin D. It is administered as a 15-minute infusion every 14 days until the hCG level reaches a normal level, followed by a further three cycles to complete the treatment.

Are there any side effects with Actinomycin D?

Yes. These can vary from patient to patient and may include some of the side effects detailed below.

**Sore mouth**
Please drink three litres of fluid (such as water, tea or fruit juice) per day. Brush your teeth with a soft toothbrush three times a day and floss regularly. You will be prescribed a regular mouth wash.

**Nausea and vomiting**
There is an increased risk of nausea compared to the low-risk treatment. Therefore you will be advised to take regularly prescribed 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.

**Myelosuppression**
As with all chemotherapy, there is a tendency for the blood count to fall. It is routine practice to check your full blood count before each course of treatment.

**Hair thinning/hair loss**
It is highly likely you will experience some level of hair thinning. It is very unusual to experience extensive hair loss with this treatment. If you are interested in having a wig please inform your key worker.
She can refer you to the wig supplier who visits Charing Cross Hospital daily. Remember, your hair will return once you complete the treatment.

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

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 above symptoms so that problems can be dealt with promptly.

If your hCG level is above 1000 you will need to change to the high-risk treatment regime as previously described.

**Counselling**
Counselling is available on the ward for both you and your partner. You can do this informally by talking to the nursing or medical staff, or formally with a trained counsellor. Your CNS/key worker can refer you to our counselling service, so please discuss this with her.

You may also wish to contact a local or national support group or organisation such as Macmillan for information and finance advice. A list of useful contact details is provided at the end of this information booklet.

**The role of the clinical nurse specialist/keyworker**
Your CNS (sometimes called key worker) 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.

The role of your CNS is to co-ordinate any investigation, treatment and follow-up care during your illness. She is there to clarify any information, discuss matters important to you, provide emotional support and refer 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.

You will be given a telephone number via which you can contact your CNS so that you will be able to get in touch with her if you have any worries or need further information when at home.

How long does treatment last?

It is difficult to give a precise time, as it varies between individuals. However, we aim to return hCG levels to normal, which is below five. We will then give you at least six more weeks of treatment, to make sure that the hCG levels do not rise again. Therefore, as a rough guide, it could be between three and four months, occasionally a little longer.

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 (see contact details at the end of this booklet). You can also ask nursing staff for further details.
What happens when I’m ready to leave hospital?

Before you leave hospital, your CNS/key worker will supervise the arrangements for your discharge home. Please make sure that you have all the items on the discharge checklist on page 14 before you go home.

It is essential that you see the clinical co-ordinator, based in the medical oncology department, east wing, first floor, Charing Cross Hospital before you go home to collect the letters for your local hospital as well as the boxes to send your blood serum samples to us.

The blood samples can be taken at your local hospital and will be needed twice a week until your hCG is normal, then once a week after that. This is necessary for all patients. The clinical co-ordinator will also give you instructions for your follow-up schedule.

Discharge checklist (low-risk patients only)

- three courses of methotrexate (12 injections)
- folinic acid tablets
- one extra folinic acid tablet (to complete your current course)
- anti-sickness tablets
- mouthwash
- sharps bin (for cytotoxic waste)
- home spillage kit

Reminders
- hCG blood test needs to be done twice a week
- store injections in a cool place, away from direct sunlight
- for low-risk treatment you must have a full blood count test once a fortnight, a day or two prior to each cycle of treatment

**Low-risk treatment patients**
If you are on low-risk treatment, we will arrange for the nurse at your GP surgery or local oncology day care centre to give you the rest of your injections.

On completion of the initial three courses of treatment (six weeks), we will ask you to come to the outpatient clinic at Charing Cross Hospital for a check-up. Further courses of treatment will be prescribed if necessary.

**High-risk treatment patients**
If you are on high-risk treatment, you will need to come to Charing Cross Hospital for the EMA chemotherapy. However, we can arrange for the CO to be given at your local hospital.

**Is there anything I need to avoid during and after treatment?**

Yes. You should avoid exposure to the sun and avoid using sun beds, as your skin may be more sensitive than usual. Use a total sun block (factor 25 or above) on exposed areas such as the face, neck, hands and feet. You should continue to do this for one year after 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, dentists and people with coughs and colds until you are fully fit again.

What about sex and contraception?

If you wish, you can have sex during treatment, provided it does not cause or aggravate any bleeding. You must take precautions against becoming pregnant and should use 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.

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 hydatidiform mole or a new pregnancy.

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. If you were using a ‘cap’ before, you will need to be fitted for a new one, as the size of your cervix may have changed.

Going through treatment may affect the way how you feel about yourself. If you would like discuss any concerns, please speak with your CNS/key worker.

Follow-up schedule

You will need to send blood serum samples twice a week until your hCG levels are normal, then every week until your six-week check-up or until treatment stops. Once your treatment is completed, you will need to continue sending samples according to the schedule below.
Mont -6

Serum and urine samples every two weeks

Months 7–12

Urine samples only every two weeks

Year 2

Urine sample every month

Year 3

Urine sample every two months

Year 4

Urine sample every three months

Year 5

Urine sample every four months

Year 6 and for life

Urine sample every six months

**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 distension (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 six weeks afterwards, due to risk of infection. If you experience a high temperature or fever, or notice any swelling or soreness, please contact your GP or the ward as you may have an infection.
When can I try to get pregnant again?

You should wait for 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 got rid of the hydatidiform mole. It also ensures your baby has the best possible start when you are fully recovered.

What is the risk of me having another hydatidiform mole?

Eighty to ninety per cent of women trying for a baby after treatment have gone on to have normal pregnancies and babies. Although we cannot guarantee that you will not have another hydatidiform mole, 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.

For the future

As you approach the menopause, you may wish to take hormone replacement therapy (HRT) and as far as we know to date, this is safe. You may find once your treatment is completed and you are free to carry on with normal life, certain issues and concerns can arise. These can include impact on relationships, future health concerns or further pregnancy worries. If this is the case for you, please bear in mind that you can contact us for further support at any time.

Contacting the trophoblastic team
Imperial College Healthcare NHS Trust has a Macmillan navigator service for access to your CNS and other members of the clinical team.

Navigators can also help with queries and provide a range of other information, help and support relating to your care. The service is available Monday to Friday 08.00–18.00. Telephone: **020 3313 0303**

**Other useful contact numbers**

Charing Cross Hospital switchboard 020 3311 1234

Ward 6 north 020 3311 1915

Ward 6 south 020 3311 1918 or 020 3311 1920

Screening and registration office 020 3311 1409

(this is where the clinical co-ordinator is based Monday to Friday 09.30–12.30 and 14.00-17.00)

Janette De-Aristizabal (counsellor) 020 3313 5553
Email: janette.dearistizabal@imperial.nhs.uk

For urgent advice outside of normal working hours phone the switchboard and ask the operator to page the on-call oncology registrar. Then wait on the line for the registrar to respond.

**Sources of information and support**
You may also like to visit the Charing Cross Hospital trophoblast disease service website. This offers information about Charing Cross Hospital, answers frequently asked questions and provides more information about treatments.
www.hmole-chorio.org.uk

**Miscarriage Association**
Helpline: 01924 200799 (Monday to Friday, 09.00-16.00)
www.miscarriageassociation.org.uk

**Molar pregnancy**
This website provides information and support to women who are currently, or have previously suffered from, hydatidiform mole.
www.molarpregnancy.co.uk

**Macmillan Cancer Information and Support Service at Charing Cross and Hammersmith Hospitals**
The information centre at Charing Cross Hospital and the infopod at Hammersmith Hospital provide emotional and practical support, as well as signposting advice to anyone affected by cancer. These drop-in services are set in friendly, non-clinical environments in which people affected by cancer can discuss private and emotional needs with dedicated Macmillan information professionals.

The information centre is located on the ground floor of Charing Cross Hospital and is open (except bank holidays):

Monday and Friday, 09.00–17.00
Tuesday, Wednesday, Thursday 09.00–16.00

Telephone: **020 3313 0171**
The infopod is located on the ground floor of the Garry Weston Centre at Hammersmith Hospital and is open (except bank holidays):

Monday and Tuesday 09.00-17.00
Wednesday, Thursday, Friday 09.00-16.00

Telephone: 020 3313 4248

**Macmillan Cancer Support Helpline**
This is a free helpline for people affected by cancer who have questions about cancer, need support or just someone to talk to. It is open from Monday to Friday, 09.00–20.00 (interpretation service available). Telephone: 0808 808 0000

**Maggie’s Cancer Caring Centre**
Maggie’s is a cancer charity that provides emotional, practical and social support that people with cancer may need. This drop-in centre combines striking buildings, calming spaces, professional experts offering support, and the ability to talk and share experiences with a community of people who have been through similar experiences. Maggie’s West London is located in the grounds of Charing Cross Hospital but please note it is independent of our hospital. The centre is open Monday to Friday, 09.00-17.00. For more information please call 020 7386 1750.

**Information Prescription Service**
This service contains reliable and accurate cancer information to help patients manage their health more effectively. Log onto www.nhs.uk/ips and enter your condition to start using the service.
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 3313 0088 (Charing Cross, Hammersmith and Queen Charlotte’s & Chelsea hospitals), or 020 3312 7777 (St Mary’s and Western Eye hospitals). You can also email PALS at pals@imperial.nhs.uk. 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 express your concerns in writing to:

Complaints department, fourth floor, Salton House, St Mary’s Hospital, Praed Street, London W2 1NY.

Alternative formats

This leaflet can be provided on request in large print, as a sound recording, in Braille, or in alternative languages. Please contact the communications team on 020 3312 5592.

We have a free and premium wi-fi service at each of our five hospitals. For further information please visit our website: www.imperial.nhs.uk