

Cancer services

Life after gestational trophoblastic disease

Information for patients, relatives and carers

Introduction

This booklet is designed to give you some information now that you have completed your treatment for gestational trophoblastic disease. We hope it will answer some of the questions that you or those who care for you may have. This booklet is not meant to replace the discussion between you and your medical team but aims to help you understand more about what has been discussed.

What happens now I have completed treatment?

Once you have had your six-week check-up, we will not usually need to see you at Charing Cross Hospital again unless otherwise discussed.

However, you do need to continue with the follow-up by sending in serum or urine samples or both according to the schedule below, we will advise you how to do this.

Months 1 to 6	serum and urine samples every two weeks
Months 7 to 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 to 10	urine sample every six months

Occasionally we may need to monitor you for longer, for example if you have been treated for a Placental Site Trophoblastic Tumour or Epithelioid Trophoblastic Tumour.

Contacting your medical team

Once you have completed your six-week check-up, you can still contact us via telephone or email. Your clinical nurse specialist, the screening service, counsellor and doctor are still available to support and inform you whenever you need it.

Please do not hesitate to contact us.

My pregnancy hormone (hCG) is higher than normal – what does that mean?

The most obvious reason for a rise in your pregnancy hormone level is pregnancy. If we know that you are not pregnant, it may be that:

- your pituitary gland is producing a little hCG, which is being detected in the hCG tests. This can happen pre-menopause, during or post-menopause. It does not necessarily mean that the disease has returned
- the hCG level is a false reading. This can be checked by repeating the same test and by using another type of hCG test

Fatigue

Fatigue can vary considerably from person to person. It can last from a couple of months to a year, sometimes longer. It is important to try to maintain normal activities as such as possible and increase your exercise levels gradually over the course of a few months.

Skin care

Please avoid sun exposure for a year after chemotherapy. If you cannot avoid sun exposure please wear a factor 50 sunscreen, a hat and long-sleeved clothes.

Hair care

For about 6 months after treatment, please avoid:

- applying any bleach or other harsh hair products on your hair
- using chemical hair straightening products

It's safe to use a use gentle shampoo, such as baby or children's shampoo.

When will my periods return?

Once the hCG level falls to around 50, your periods may return. However, this varies considerably. It can take up to six months for some women. You may experience hot flushes

or night sweats until your ovaries start functioning again. Once your hot flushes go, your periods will likely return soon after that.

Contraception and future pregnancies

You can use any form of contraception that suits you unless your clinical team advises otherwise.

We normally recommend that you wait one year from when the treatment finishes before you start trying for a baby. Our advice to wait is due to the small risk of relapse (4 per cent overall), most of which would usually 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.

Fear of recurrence

Fear of the disease returning is common for women following treatment. It may lead to anxiety over minor aches and pains that can be quite vague in nature.

As long as the hCG level is normal (below 5), we are usually reassured that it is not the disease returning. However, you should call us to discuss these symptoms and concerns so that we can make an assessment.

It is important that you maintain the hCG follow-up schedule so that we can monitor you effectively.

Holiday insurance

You should always ensure you have travel insurance when travelling abroad for any period of time. You must always declare this diagnosis to travel insurance companies. There are travel insurance companies that specialise in cover for those who have or have had medical conditions. Please ask your clinical nurse specialist for further advice if you are finding this difficult.

Menopause

The treatment can bring the menopause forward by approximately three years. The average age for a woman to go through menopause is 52 and therefore you may start at 49 years of age.

Emotions

Having a molar pregnancy can challenge your emotional and physical well-being. Losing a pregnancy, combined with a cancer diagnosis, can trigger many different feelings.

For some, the emotional healing takes as long as the physical healing, for some it takes longer. Even if the pregnancy ended very early, the feelings of loss can be very difficult to process for both the person who was pregnant and their partner.

The experience of grief can be unexpected; you may feel angry or sad, you may feel numb or confused. It is important to know there is no wrong way to feel and there is no wrong time to feel it.

For some people, thinking about the future can be difficult. It can be frightening to imagine moving forward or future family planning.

Remember, this is a rare and curable cancer. When you are ready, it will not affect your ability to live a full life or build a family if you wish to do so.

You or someone close to you may be struggling to process this experience. So, if more support would help, talk to your doctor or a qualified counsellor. Talking can provide great relief. It can help you to process what has happened.

At Charing Cross Hospital, we have a counsellor supporting the Gestational Trophoblastic Disease Centre. If feel that counselling would benefit you and your partner, please ask your CNS or doctor.

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~~

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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