

a patient's guide

Now that your chemotherapy for ovarian cancer is finishing

Patient Information Series PI 41a



Mount Vernon
Cancer Centre

Contacts

Chemotherapy Suite: 020 3826 2236
[Mon - Fri, 8.00am - 5pm]

Ward 11 020 3826 2040
[24 hours]

Your oncologist's secretary:

Macmillan Gynaecological Clinical Nurse Specialist:

Office no: 020 3826 2091

Mobile no: 07917 078214

Pharmacy: (Mount Vernon) 020 3826 2505
[Mon - Fri, 9am - 5pm, Sat 9.30am - 12 noon]

Pharmacy patient help line: 01438 286150
[Mon - Fri 2pm - 4pm]

or email for response the next working day:
medinfo.enhtr@nhs.net

**For urgent medical advice:
24 hour Acute Oncology Service
Mount Vernon Cancer Centre: 07825 028855**

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Contents

Contacts	2
Introduction	4
How might you feel?	4
Will I have follow-up appointments?	5
Why do we continue to see you?	5
What should I do if I get any symptoms?	7
Frequently Asked Questions	8
Where can I get more information about how to treat my hair as it grows back?	9
Other help and support	10
If you normally pay for NHS prescriptions...	10
Consent	11
Identification	11
Pregnancy/fathering a child	11

Introduction

This leaflet is a guide to help you live now that your chemotherapy for ovarian cancer is finishing.

It talks about how you might feel, the follow-up you can expect and what to do about any symptoms which worry you.

How might you feel?

As you finish your treatment you may just want to 'get up and go' and pick up your life as it was before your treatment. However, any unwelcome side effects, including tiredness, may remain for the next few weeks and it can be some months before you begin to notice any improvement. Remember, you may need to change your lifestyle while you recover from your treatment.

Getting back to a 'normal' routine is fine, but allow your body time to recover. If it is more than four to six weeks since your major surgery and all your wounds have healed, then exercise can also be good for helping you as you move on.

Remember that we are all different. We all respond and recover at different rates. Pace yourself and do whatever you feel capable of doing without putting yourself under too much stress.

If you feel you would like to talk to someone about life after treatment, you can drop in to the Lynda Jackson Macmillan Centre. They also offer counselling sessions to help you if you are finding it difficult to adjust. The centre's team can give you information on how to join a 'Hope' course which is a six-week course to help you move on after cancer treatment.

Will I have follow-up appointments?

The surgeons and oncologists (cancer specialists) meet every week at a multi-disciplinary team meeting. This gives them a chance to discuss any concerns they might have about you. The team will have written to your GP explaining the treatment you have had, giving details of your follow-up appointments.

A member of the oncologist's team and/or your gynaecologist will normally see you at regular intervals for up to ten years after your treatment. They can see you earlier than your pre-arranged appointments if you have any problems. Please contact your oncologist's secretary via the hospital switchboard on 020 3826 2020.

It may be possible to see your own GP for some checks - your oncologist will tell you if this would be suitable.

It is a good idea to make a list of any questions and concerns you have and take it with you when you see the doctor.

If you have waited longer than expected for your follow-up appointment to be sent to you, please contact your oncologist's secretary via the hospital switchboard on 020 3826 2020.

Why do we continue to see you?

We ask you to attend follow-up clinics so we can monitor you for any remaining side effects of your treatment and for any signs of cancer coming back (relapse). If you have any symptoms or concerns, this is a chance to discuss them and to ask any questions that you may have.

Women diagnosed with early stage ovarian cancer may be cured but will need to attend three-monthly visits for the first two years to be monitored. After this the visits may be reduced to twice a year and then annually.

Only a small number of women who present with advanced disease can be cured by surgery and chemotherapy. An increasing number of patients who are not cured are living many years even after their cancer has come back. For these patients, we try and organise follow-up so that they survive as long as possible striving for the best quality of life.

An increase of a protein in your blood called CA-125 has been shown to be linked with ovarian cancer. Levels can start rising months or even years before there are any other signs of the cancer coming back. However it is your symptoms, rather than your blood results (CA-125) that will indicate if you should consider further treatment.

For most patients whose cancer has come back, further treatment will help manage your symptoms. Research shows that the best time to give further treatment is when symptoms arise. Starting treatment earlier does not make you live longer. It usually involves more chemotherapy and sometimes surgery and/or radiotherapy.

Because of these issues, when you start your follow-up you will be offered three options:

1. Not to have routine CA-125 blood tests if you are well and have no symptoms that suggest your cancer has come back (relapsed). This is what we recommend, as it can lead to a better quality of life and is safe, as long as you contact us as soon as any problems develop or if you are worried about recurrent or new symptoms. We are able to give you a blood test request form (CA-125) so you can have the test done straightaway, if you start feeling unwell.
2. To have a CA-125 blood test at each visit but not be told the results. This option can be used if you are in a clinical trial where routine CA-125 measurements are done for the study.
3. To have a CA-125 blood test at each visit, so that you have some advance notice as to when you might require further chemotherapy. Often patients start by having their CA-125 done at each visit but then choose not to continue as they feel more confident.

We do not routinely organise scans unless you are in a clinical trial. However, we would organise a scan and a CA-125 blood test if you developed symptoms suggesting your cancer might be returning (and/or you had a rising CA-125 if this is being measured).

What should I do if I get any symptoms?

Anxieties may remain as you finish your treatment. You are likely to be more aware of your body now that your treatment has finished and may notice even small changes in how you feel from day to day.

If you find you become anxious when you have aches and pains, coughs and colds, remember these are not necessarily linked to the cancer coming back. They can be caused by other things.

If you have any symptoms that do not go away, or any of the symptoms listed below, you must tell us about them.

If you are concerned by any of the following symptoms:

- abdominal pain lasting more than four - eight hours, especially if it is 'colicky' or intermittent
- abdominal swelling or feeling a lump
- change in bowel habit lasting more than a few days without any cause such as going on holiday/change of diet
- needing to pass urine more often or new leaking
- nausea, vomiting, diarrhoea, constipation or loss of appetite that cannot be attributed to food poisoning or community infection
- vaginal or rectal bleeding
- loss of appetite or weight
- a feeling of abdominal bloating (especially if it occurs on waking in the morning or after only a small meal) that lasts for more than two - three days
- other symptoms you have been told to watch for or any other symptoms that do not go away

... then you should:

- contact the specialist nurse (see page 2) or
- contact your oncologist's secretary via the Mount Vernon Cancer Centre hospital switchboard on 020 3826 2020 or call 020 3826 2442 or
- call the hospital switchboard and ask them to connect you to a member of your oncologist's team

They will either arrange an earlier appointment for you, or get a doctor to speak with you to decide if you should see your GP first.

Do not ignore anything. A phone call to the right person may put your mind at rest or help to deal with the problem. We are here to continue to help and support you (see contacts at the beginning of this booklet).

As you get closer to your follow-up appointment, you may feel a little nervous or uncertain. This is quite usual and each person addresses these feelings differently.

Frequently Asked Questions

How do I obtain travel insurance?

Visit the LJMC or the Macmillan Cancer Support website www.macmillan.org.uk for their booklet 'Travel and Cancer'.

Macmillan also have a travel insurance blog, where people have shared their experiences of gaining sensible travel insurance <https://community.macmillan.org.uk/cancer-blogs>.

My arthritis improved while I was receiving chemotherapy. Will it get worse now that I have stopped?

You may have found that your arthritis improved while you were receiving chemotherapy. If so, you may find that your arthritis symptoms 'flare up' before settling back to how they were before chemotherapy, now that this has stopped.

Where can I get more information about how to treat my hair as it grows back?

You can get information about caring for your hair on these websites:-

www.macmillan.org.uk/hairloss

www.cancerhaircare.com

www.mynewhair.org

or telephone:-

Macmillan Cancer Support on 0808 808 00 00 or

Cancer Hair Care on 01438 488 082

MyNew Hair 01798 812 547

or call into the LJM.C.

Other help and support

People who have cancer often say that, during their illness, they experience a range of emotions. Many find it to be a stressful, anxious and confusing time.

If you have any questions or concerns about cancer and your treatment, are struggling to cope or need some support, please visit the Lynda Jackson Macmillan Centre (LJMC). Please feel free to drop in before, during or after any of your visits to the Cancer Centre.

The team at the LJMC works as part of the overall team caring for you to provide help, support and information in a relaxed setting to help you better cope with cancer and its treatment. Your family and friends are also welcome to visit the centre or call the Helpline.

A range of support services are available at the centre. These include complementary therapy, relaxation sessions, counselling and financial advice. Please ask for more details.

You do not need an appointment to visit the LJMC which is located next to the Chemotherapy Suite by Gate 3. If you are unable to get to the LJMC, you can call the Helpline on 020 3826 2555.

Please see the back page of this leaflet for more information.

If you normally pay for NHS prescriptions...

People undergoing treatment for cancer do not have to pay NHS prescription charges if they have a valid medical exemption certificate. To get an exemption certificate, ask your GP for an application form.

Mount Vernon Cancer Centre is committed to ensuring that patients receive the best quality of care regardless of their gender identity or sexual orientation.

Consent

It is a legal requirement to have a signed consent form from you before the start of your treatment.

If you have already been given one of these forms, please bring the completed form with you when you come for your first appointment.

If you have not been given a form, this will be discussed with you at your first appointment.

Identification

Please note that it is a legal requirement for the staff to check your name and details against your treatment sheet every time you attend.

Pregnancy/fathering a child

Patients must not be pregnant or become pregnant, or father a child, during a course of treatment or for some months afterwards. **Please discuss this with your cancer specialist.**

If you are of child bearing capacity we ask that you inform a member of staff. It is our duty of care to enquire whether individuals may be pregnant or breastfeeding. This information will be kept in strict confidence.

If you think there is a chance, however small, of you or your partner being pregnant during treatment, it is extremely important that you discuss this with your oncologist, radiographer or nurse as soon as possible.

This publication has been produced by the Information team at Mount Vernon Cancer Centre. Contributors include health professionals, patients and carers who have expertise and experience in the topics covered by this publication. All our publications are reviewed and updated regularly. If you would like any details of the references used to write this information please contact the Information team on 020 3826 2555.

**Questions or concerns about
cancer and treatment?
Struggling to cope?
Need some support? Need to talk?**

Drop in to the Lynda Jackson Macmillan Centre
or call the support & information helpline

We will listen to your concerns, answer your questions
and guide you to further information
and services to help you

cancer treatment	practical support
side effects of treatment	headwear workshops
day-to-day living with cancer	exercise
benefits advice	diet and nutrition
counselling	health and wellbeing
someone to talk to	talking to family and friends
emotional support	Look Good Feel Better
complementary therapy	self-help courses
relaxation services	life after cancer

The Lynda Jackson Macmillan Centre is situated between the
Cancer Centre and Gate 3 (White Hill)

Opening hours: Monday–Friday 9.30am–4.30pm

020 3826 2555

www.ljmc.org

Supporting people affected by cancer
from diagnosis, through treatment and beyond