



Your guide to self managed follow-up after cancer of the womb

Patient and Carers Information Leaflet



Specialist Support

This leaflet can be made available in another language, large print or another format. Please speak to the Ward Manager who can advise you.





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Your personal details

Name:

Hospital number:

Date of diagnosis:

Diagnosis:

Surgical treatment and dates:

Medical treatment and dates:

Radiotherapy treatment and dates:

Surgical consultant:

Oncology consultant:

Named gynaecology oncology specialist nurse:

Care co-ordinator:

Your treatment plan:



Introducing supported self management

In the past, it has been traditional for patients who have completed their treatment for womb (endometrial) cancer to be seen at regular intervals by their oncologist or surgeon in follow-up clinics.

Although some patients find these pre-arranged visits useful and re-assuring, many patients find these hospital visits a source of great anxiety and not particularly helpful, unless they have a particular concern they wish to discuss. There is now very good evidence to show that following-up patients in this way does not prevent cancer returning and does not increase life expectancy. Like some other gynaecology cancer services in other parts of the UK, Southampton Gynaecology services now uses a new system that allows you to arrange follow-up appointments as and when you need them, within the five year period after the end of your treatment.

This booklet contains details of how and when to contact the Gynae-oncology team and arrange follow-up, plus information you may find useful as you recover after your treatment. It also contains details about your personal type of womb cancer, the treatments you have received so far and any medication that you will need in the future – your treatment plan.

Supported self management

Supported self management puts you in control of your hospital follow-up. Once you have received this booklet you will no longer be given routine follow-up clinic appointments at regular pre-set intervals. Instead, you will simply be able to contact the Gynae-oncology service directly to arrange a follow-up appointment if you have any concerns.

After five years you will need to go back to see your GP if you have any concerns or notice anything unusual. Please notify your consultant's secretary if you change your address in case, for any reason, the hospital needs to contact you in the future.

When to contact the Gynae-oncology team

You should arrange a review by a member of the Gynae-oncology team if you have concerns about any of the following issues:

- New medical symptoms that you are worried could represent a relapse of your womb cancer.
- Problems related to your original treatment for your womb cancer.
- Possible side effects from your chemotherapy or radiotherapy treatment.

How to arrange a review

You can contact the Gynae-oncology team on:

- Telephone: 023 9228 6000 Ex 4226
- Email: gynae.oncology@porthosp.nhs.uk

Office hours: Monday to Friday, 08.30am to 16.30pm

Please leave a brief message and a contact telephone number on our answer phone. You will be contacted by one of our gynae oncology nurse specialists within one working day. They will briefly discuss the nature of your concern with you and if necessary arrange a clinic appointment within two weeks of your phone call. Your GP can also use this number to contact us.

Recovering from your surgery

There is very good evidence that encouraging patients to return to normal as quickly as possible reduces problems and complications. This is called 'enhanced recovery' and you will have received information about this during your hospital admission.

Your rate of recovery will depend upon many things. Because of this, it is difficult to give an exact time line. You should try to do a little more each day and use common sense to determine what is right for you.



If you have had keyhole surgery the recovery should be rapid and you should be able to do most things after around two or three weeks. If you have had a traditional, larger incision (cut), recovery can be a little longer. By six weeks many patients are almost back to normal.

Further reading:

- *Understanding womb (endometrial) cancer* – available from Macmillan
- Cancer Support www.macmillan.org.uk
- *Hysterectomy: the basics* – this booklet can be downloaded from the Hysterectomy Association <http://www.hysterectomy-association.org.uk/>

Recovering from your radiotherapy

Short-term side effects

Radiotherapy can cause acute side effects which occur during treatment, and tend to peak at the end or up to two weeks after finishing treatment. If you have a skin reaction, this should resolve and completely heal by four to six weeks after radiotherapy. Many patients feel tired both during and after radiotherapy. This is generally worse if you also received chemotherapy. Tiredness tends to improve about six weeks after completing radiotherapy but it can often take several months to recover.

Going out in the sun

You should take sensible precautions in the sun and avoid getting sunburn. You should cover the treated area as it may be more sensitive. Use high factor sun cream – at least factor 20. Once the skin reaction has settled you can return to activities such as swimming.

This is normally possible within a month of treatment finishing.





Long-term side effects

Some women get long-term bladder or bowel problems after pelvic radiotherapy. Other possible effects are damage to the bones or lymphoedema (swelling of the legs because of narrowing or blockage of the lymph drainage channels). Radiotherapy can make the vaginal walls less stretchy, which can lead to difficulty with having sex or medical examinations. To maintain the health of the vaginal walls, your gynae/ oncology nurse specialist or specialist radiographer will have advised you how to use vaginal dilators from about two to eight weeks after the radiotherapy has ended.

Most women will have some change in the way that their bladder or bowel works, and some may have vaginal changes and changes in the physical and emotional feelings associated with sex. The impact of these side effects varies from person to person. For some women the effects may be minor and will not affect their daily life.

Some women may need to make some changes to their life to be able to deal with the effects. For a small number of women the changes may be difficult to cope with. The changes can mean that they have to restrict their activities, reduce or give up work, and limit socialising because of needing to stay close to a toilet. Much can be done to help if this happens. Your cancer specialist or GP may be able to help you. They can also refer you to a doctor who has a special interest in treating long-term side effects of radiotherapy. These doctors are not in every hospital, so you may need to travel to see one.

Further reading:

- *Understanding radiotherapy*
- *Managing the late effects of pelvic radiotherapy in women*
- *Sexuality and cancer*

Available from Macmillan Cancer Support
www.macmillan.org.uk



Recovering from your chemotherapy

Tiredness

Almost all women feel very tired by the end of their chemotherapy. This can then get worse if they are then receiving radiotherapy. Your tiredness should start to improve one to two months after your last cycle of chemotherapy and then steadily improve. However it can take at least six months before your energy levels will return to normal and some women still feel tired 12 to 18 months after the end of their treatment. If you gradually increase your levels of physical activity over time you will find that this will help you to do more and recover your energy levels more quickly.

Hair growth and colouring hair

Most women find their hair starts to grow back three to four weeks after their last chemotherapy session. The hair grows slowly to begin with and can be quite thin and fluffy, but over time the hair thickens up and after six months most women will have a good head of hair again. As your new hair will be rather delicate, we recommend you wait for six months before using chemical, permanent or semi-permanent dyes on your hair. However, it is safe for you to use herbal or non-permanent dyes.

Putting on weight

It is quite common for women who have had chemotherapy for cancer to gain some weight during their treatment. The chemotherapy drugs themselves do not cause weight gain but the steroid tablets we use as anti-sickness tablets can increase appetite. Many women also find their diet changes while they are on chemotherapy and they do less exercise than usual because of the tiredness that it can cause.





Recovering feeling in your fingers and toes

If you have developed pins and needles or numbness of your fingers or toes during your chemotherapy treatment, this should gradually improve in the weeks and months following the end of your treatment. However, you may find that it initially gets worse after your last treatment before it starts to get better. A small number of patients may find that sensation in their fingers or toes remains altered permanently.

Long-term side risks of chemotherapy

There is a very low risk that patients treated with chemotherapy can develop different, unrelated cancer, years later. Please ask your oncology consultant for further information about this. These issues will have been discussed with you before you began your chemotherapy treatment.

Further reading:

- *Understanding Chemotherapy* - available from Macmillan Cancer Support www.macmillan.org.uk

Managing menopausal symptoms

Most women developing womb cancer will have already gone through the menopause. In those women who have not gone through the menopause, surgery for womb cancer includes removing the ovaries, which will lead to menopausal symptoms. This means pre-menopausal women will then go through the menopause.

Hot flushes and night sweats are the most common menopausal symptoms, but many women also notice weight changes, vaginal dryness and changes in libido and mood swings.



Hormone replacement therapy

Hormone Replacement Therapy (HRT) is generally not routinely recommended for use in women who have been treated for womb cancer. However, if symptoms are affecting quality of life, the risks and benefits of starting HRT can be discussed with your consultant and/or gynae/oncology nurse specialist.

If you are suffering from vaginal dryness, vaginal lubricants such as Sylk, Replens MD or KY-Jelly can be helpful. If these do not solve this problem then a topical oestrogen cream may help. However, this should be discussed with your consultant.

Herbal therapies

Some natural remedies, such as black cohosh and red clover are advertised for the relief of menopausal type symptoms. However these contain plant oestrogens (phyto-oestrogens) and are not recommended for use by women who have had womb cancer. Evening primrose oil is safe to use and some women do report that it is helpful for menopausal symptoms. However, there is no scientific evidence to prove this. There is no good evidence for the use of vitamin E for hot flushes and vitamin E supplements may even be harmful, especially for people with heart disease.

Additional help

Do tell your gynae/oncology nurse specialist or GP if your menopausal symptoms are troubling you. Several prescription drugs can be effective in reducing hot flushes and your doctor will be able to discuss the potential benefits and side effects of these medications with you. Alternatively, some women find relaxation type complementary therapies such as acupuncture, hypnotherapy, massage or aromatherapy helpful for their symptoms.

Further reading:

- www.menopausematters.co.uk





Getting back to 'normal'

Reaching the end of your treatment can be a difficult time for many patients.

Although you will feel relieved that your treatment is finally over, you may also experience a feeling of 'what now'? and find that you miss the security of being seen at the hospital on a regular basis. Most patients will also find that it takes rather longer than they expect to recover fully from their treatment.

Support

You may already have found that people have different ways of living after their treatment and get support from speaking about their experience. Ask the gynae/oncology nurse specialists for details of local support groups if you think it might be helpful.

The effects of pelvic radiotherapy may be difficult to talk about. It can be embarrassing to say that you have problems with your bowel, bladder or sex life. However, doctors and gynae/oncology nurse specialists are used to discussing intimate problems. You can tell them exactly what is happening to you. They will then be in the best position to help. Your doctor or nurse can also refer you to a Continence Adviser or Relationship and Sexual Therapist, if needed. The Bladder and Bowel Foundation (see end of leaflet) can give you information and support on bladder and bowel problems.

Resuming sexual activity

Treatment for endometrial cancer can affect your sex life in several ways. If you haven't already had the menopause, removing the ovaries means that you'll go through an early menopause, causing vaginal dryness and loss of sexual desire.

Radiotherapy can make your vagina narrower and less flexible, so having sex may become more difficult.



Your gynae/oncology nurse specialist or specialist radiographer will have advised you how to use vaginal dilators from about two to eight weeks after your radiotherapy has ended.

It's not uncommon for women to lose interest in sex after treatment for endometrial cancer. Your treatment may leave you feeling very tired. You may feel shocked, confused or depressed about being diagnosed with cancer and may be grieving the loss of your fertility. It's understandable that you may not feel like having sex while having to cope with all this. Try to share your feelings with your partner. If you feel that you have problems with sex that aren't getting better with time, you may want to speak to a counsellor or a sex therapist.

Further reading:

- *Adjusting to life after cancer treatment*
- *The emotional effects of cancer*
- *Talking about your cancer*
- *How treatment for womb cancer may affect your sex life and fertility*

Available from Macmillan Cancer Support www.macmillan.org.uk

- You can also ask to be referred to a Psychosexual counsellor.
- Your GP can arrange this or ask you Clinical Nurse Specialist.

Returning to Work

You can return to work whenever you feel ready to do so. All jobs are different so it is difficult to be specific. Some women find they can work throughout their chemotherapy and/or radiotherapy treatment, while other women find they need a recovery period of several months after the end of their treatment before they are ready to return to their job.

Whenever you return, remember that it may be a shock to the system to begin with and it can be very useful to return in a phased manner, increasing your working hours over a few weeks.



The Disability Discrimination Act (DDA) covers all types of cancer and exists to protect against unfair treatment compared to others, harassment and victimisation, and unfair dismissal. If you think you are being treated unfairly when you're trying to get back to work, it's there to protect you. Disability employment advisers are based at Job Centres and Job Centre Plus.

Some questions that might be helpful to ask before returning include:

- What adjustments could your employer arrange that would make work easier for you?
- Can you reduce your hours, work flexibly or work more at home?
- Will you need to rest at work during the day?
- Is there any counselling available if you want it?

Telling friends and work colleagues about your cancer is the best way to overcome any uneasiness they may have about what has happened to you.

Further reading:

- *Work and cancer* – available from Macmillan Cancer Support

Financial concerns

A cancer diagnosis can have an effect on your income, but you may be able to get help with NHS costs, grants and certain benefits. There are a number of people you can talk to for information to see if you are entitled to any additional help if financial issues are causing you to worry. Ask your clinical nurse specialist to refer you to Macmillan, Citizen's Advice Bureau (CAB) or social work department for more information. You may be able to get help from other organisations or charities that give grants, but will need to apply through a health or social care professional, such as your gynae/oncology nurse specialist or a social worker.

Further reading:

- *Help with the cost of cancer* – available from Macmillan Cancer Support

Exercise

Most women feel tired for a number of weeks, if not months, after they have had treatment for cancer. We recommend that, once you have completed your treatment, you try to gradually increase your daily activity, with the aim of trying to build up to four or more twenty minute sessions of moderate activity each week.

Travelling abroad

Once you have completed your treatment, there is no reason for you not to travel abroad. Sometimes patients can encounter difficulties in acquiring travel insurance if they have been treated for cancer. Both the Macmillan Support and Information Centre and the Macmillan website have a list of insurers specialising in the cover of patients who have had cancer and will be able to offer advice. More information is available in the Macmillan Factsheet: Travel Insurance May 2010 available at: www.macmillan.org.uk

Diet

Enjoying a healthy diet, avoiding excessive weight gain and maintaining a moderate level of physical activity is important if you have had any cancer. There are conflicting theories about diet and cancer, which can be confusing. Most experts would agree that a healthy diet is balanced and varied and provides all the right nutrients needed.

There is increasing evidence that following a diagnosis of endometrial cancer maintaining a healthy weight, avoiding excessive weight gain, and maintaining moderate levels of physical activity, is associated with an improved quality of life and enhanced recovery.

The main things to consider in a healthy diet include:

- eat the right amount to maintain a healthy weight
- eat plenty of fresh fruit and vegetables
- eat plenty of foods rich in fibre and starch, and whole grains
- avoid eating too much fatty food especially saturated or animal fats
- avoid sugary food and drinks
- drink in moderation, and avoid drinking alcohol on at least two days a week.

These dietary guidelines are also suitable for people who don't have cancer and can be followed by members of your family. They may reduce the chances of getting heart disease and diabetes as well as certain types of cancer, including breast and prostate cancer.

A summary of the evidence regarding diet, lifestyle and cancer prevention was produced in February 2009 by the World Cancer Research Fund. There is a lot of information available on healthy eating from organisations such as the Food Standards Agency and NHS Choices.

Further reading:

- *Diet and cancer* – available from Macmillan Cancer Support
- *Lifestyle and cancer* – World Cancer Research Fund

Alcohol

Once you have completed your treatment for womb cancer there is no need to avoid alcohol entirely. We would always advise that you should not drink in excess of the Department of Health's recommendations: no more than two to three units of alcohol per day, where a unit of alcohol equals a small glass of wine, and avoiding alcohol for at least two days per week.



Dealing with worries about womb cancer returning

Am I cured?

You will find that most doctors do not use the term 'cured', as this implies that they can give you a 100% guarantee that your womb cancer will never return. Unfortunately, we can never make this promise to any patient.

What is the chance of my womb cancer returning?

The risk that your womb cancer will come back is different for every patient. However, by having the treatment recommended by your surgeon and oncologist you have minimised your personal risk of having any further problems from womb cancer as much as possible.

Will I have any tests to check that the cancer hasn't returned?

Research studies have shown us that doing regular tests on women who have no symptoms are not helpful in diagnosing relapsed womb cancer and cause unnecessary anxiety. However, if you develop any new symptoms, the appropriate investigation will be organised for you once you have been reviewed in the clinic.

I am constantly anxious that my womb cancer will return –what can I do?

It is entirely natural to feel anxious that your womb cancer will return and we recognise that this can make you feel very uncertain about the future and lead to difficulties in 'getting on with life'.

Some people find it useful to have some additional support in dealing with these feelings and benefit from counselling. This may be available from your GP, or alternatively let us know and we can refer you to the Wessex Cancer Trust for individual or family counselling.





What sort of symptoms should I inform the gynae/oncology team about?

- Vaginal bleeding or discharge. The most significant symptom to look out for is a new onset of vaginal bleeding. While most of the time this will not be of significance you should contact us using the telephone number for a check-up. For some patients who have had radiotherapy the radiation changes mean that bleeding can commonly occur after intercourse or using vaginal dilators. If this is a new symptom then you should have a check-up. If however this is a regular and predictable symptom then this is of less concern.
- Abdominal pain – pain that is constant is of most concern.
- Unexpected weight loss or loss of appetite.
- Persistent changes in bowel habit – i.e. ongoing constipation or diarrhoea.
- Persistent problems when passing urine.

Do remember, however, that some of these symptoms can also be caused by other conditions that are completely unrelated to womb cancer, so please do not become unduly anxious while awaiting your review.

Please don't hesitate to contact the gynae/oncology nurse specialist team on 023 92286 000 extension 4226 if you have any questions or concerns about your diagnosis and/or treatment. If we are unavailable then please leave a short message with your contact number and we will get back to you within one working day.



Further information and useful contacts:

Macmillan Cancer Support

Emotional and practical support for people with cancer and information about cancer types and treatments.

- Helpline: 0808 808 0000
- Financial Helpline: 0808 808 2232
- www.macmillan.org.uk

The Hysterectomy Association website

This site is about hysterectomy, rather than womb cancer. There is useful information, including a booklet you can download. The website has message boards where you can exchange information with other women about hysterectomy and recovering from it.

- www.hysterectomy-association.org.uk

The Eve Appeal

A national appeal determined to improve awareness and funding of research into gynaecological cancers whose vision is a future where fewer women develop and more women survive gynaecological cancers.

- www.eveappeal.org.uk

The Bladder and Bowel Foundation

Provides information and advice on a range of symptoms and conditions related to the bladder and bowel.

- Helpline: 0800 031 5412
- www.bladderandbowelfoundation.org

Cancer Research UK

Information, research and details of clinical trials

- Helpline: 0808 800 4040
- www.cancerresearchuk.org





National Cancer Institute Information on womb cancer (USA)

The American National Cancer Institute's patient information site. Its section on womb (endometrial) cancer is detailed and comprehensive.

- www.cancer.gov/types/uterine

College of Sexual and Relationship Therapists

Offers counselling and psychotherapy and can give details of local counsellors.

- Telephone: 020 8543 2707
- www.cosrt.org.uk

Turn2us

UK charity helping people access money that may be available to them – through welfare benefits, grants and other help.

- Telephone: 0808 802 2000
- www.turn2us.org.uk

Weightwatchers

- <http://www.weightwatchers.co.uk/index.aspx>



Local contacts:

Portsmouth Macmillan Cancer Information and Support Centre

B level, Queen Alexandra Hospital.

- Telephone: 023 9228 3323
- www.porthosp.nhs.uk/departments/maxfac/Macmillan-Centre/welcome-to-the-macmillan-centre-at-qa-hospital.htm

Harbour Cancer Support Centre

The Bus Station

South Street

Gosport. PO12 1EP.

- Telephone 023 9250 1503

Wessex Cancer Trust

Local charity providing information, counselling, complementary therapies.

Cosham High Street. Mon – Thurs 10.00am – 4.00pm

- www.wessexcancer.org.uk

Hampshire Macmillan Citizens Advice Service

A confidential and impartial service providing access to advice on welfare benefits, employment, finance, debt, housing and general advice areas for people living in Hampshire excluding the Isle of Wight. Outreach service available at the Southampton Macmillan Support and information centre.

- Telephone: 0844 847 7727

Quitters stop smoking services

Support for people who want to stop smoking.

Hampshire

- Telephone: 0845 602 4663 www.quit4life.nhs.uk

Southampton

- Telephone: 023 8051 5221
www.southamptonhealthyliving.org.uk/stop-smoking/





Health Trainers

Living with Cancer? We'll help you get active.

There is a 12 week one to one service available, providing support and encouragement with lifestyle changes helping you improve your well being.

At the following leisure centres:

Oasis Wellness Centre

Queen Alexandra Hospital .
Southwick Hill Road.
Cosham. PO6 3LY

- Telephone: 023 9228 3333
- www.oasiswellnesscentre.org.uk

Pyramids centre

Clarence Esplanade.
Portsmouth. PO5 3ST

- Telephone: 023 9279 9977
- healthreferral.pyramids@bhlive.co.uk
- www.pyramids.co.uk

Fareham Leisure Centre

Park Lane.
Fareham. PO16 7JU

- Telephone:01329 226370
- www.everyoneactive.com/centre/fareham-leisure-centre/

Gosport Leisure Centre

Forest Way
Gosport. PO13 0ZX

- Telephone: 023 9253 4950
- www.placesforpeopleleisure.org/centres/gosport-leisure-centre/



Horizon Leisure Centres

Havant

Civic Centre Road
Havant. PO9 2AY

- Tel: 023 9248 8477
- gymmanager@horizonlc.com
- www.horisonlc.com

Waterlooville

Waterberry Drive
Waterlooville. PO7 7UW

- Tel: 023 9224 5900

John Pounds Centre

23 Queen Street
Portsmouth. PO1 3HN

- Tel: 023 9289 2010
- healthylivingteam@johnpoundscentre.co.uk
- www.johnpoundcentre.co.uk

Mountbatten Leisure Centre

Alexandra Park
Portsmouth. PO2 9QA

- Telephone: 023 9320 0401
- stepstohealth@parkwood-communityleisure.co.uk
- www.bhliveactive.org.uk/centres/mountbatten-leisure-centre/

Havant Council of Community Services

- Telephone: 023 9244 6406

Gosport Voluntary Action

- Telephone: 0293 9258 3836
- www.gva.org.uk

Rushmoor Healthy Living:

- Telephone: 01252 362660
- www.rhl.org.uk





Charity information – Gynae Cancer Fund: To enhance the care and services for gynaecological cancer patients at Queen Alexandra. Hospital.

www.porthosp.nhs.uk/get-involved/fundraising/new_page_2.htm

Notes/Questions

Please use the space below to remind you of any questions you may need to ask.

Large empty dotted-line box for notes and questions.



Consent – what does this mean?

Before any medical professional examines or treats you they **must have your consent** or permission.

Consent ranges from allowing the doctor to take your blood pressure – rolling up your sleeve and presenting your arm is implied consent – to signing a form saying you agree to a treatment or operation.

It is important **before** giving consent that you understand what you are agreeing to. **If you do not understand – ask.** More detailed information is available on request.

Information we hold about you and your rights under the Data Protection Act

Please refer to the booklet 'Your Healthcare Information – Your rights! Our responsibilities!'

How to comment on your treatment

We aim to provide the best possible service and if you have a question or a concern about your treatment then the Patient Advice and Liaison Service (PALS) are always happy to try to help you get answers you need. You can contact PALS on 0800 917 6039 or E-mail: PHT.pals@porthosp.nhs.uk who will contact the department concerned on your behalf.

This leaflet was adapted from the leaflet designed by University Hospital Southampton with the permission of Mr Simon Crawford on behalf of the Gynaecological Oncology Team as part of collaboration between the centres.

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