

Your guide to patient triggered follow-up following endometrial (womb) cancer

Information for patients and carers



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This booklet introduces patient triggered follow-up care for endometrial (womb) cancer. It contains details of how and when to contact the Macmillan gynae-oncology clinical nurse specialist (CNS) team should you have any concerns during the next five years. It also provides information you may find useful as you recover from your treatment.

Please read this booklet carefully, and keep it in a safe place in case you need to refer to it in the future.

About patient triggered follow-up

Patient triggered follow-up (PTFU) is a system which has been designed to put patients in control of their own hospital follow-up after completing treatment for certain types of cancer.

What it means for you

Now that your treatment for endometrial cancer is complete, you will no longer receive routine follow-up clinic appointments. Instead, you will simply be able to contact the CNS team directly if you have any concerns. You will be given information about the symptoms you should be aware of, and will be asked to complete a symptom checklist once a year.

PTFU workshop

You will also be invited to attend a health and wellbeing workshop. This is an informative session during which we explain patient triggered follow-up in more detail, and give you the opportunity to ask any questions that you may have. We will discuss topics such as a healthy lifestyle and physical activity during your recovery and beyond. The environment is friendly and supportive, with each session usually attended by a small group of women (around six or eight), all of whom have been treated for endometrial cancer.

Symptom checklist

You will need to complete a symptom checklist once a year, for five years after the end of your treatment. This forms an important part of your follow-up.

The checklist is available online via My Medical Record, but can also be completed by post if you prefer. If you have any questions about the symptom checklist or using My Medical Record, please speak to your CNS.

Please notify your consultant's secretary if you change your address or any other personal details (**023 8120 6032**).

When to contact your CNS team

You should contact us if you have any of the following symptoms:

- Vaginal bleeding
- Unexplained abdominal or pelvic pain
- Unexpected weight loss or loss of appetite
- Changes in bowel habits
- Problems passing urine

It's important to remember, however, that some of these symptoms can also be caused by other conditions completely unrelated to endometrial cancer, so please do not become unduly anxious while you are waiting to speak with your CNS.

How to contact us

Clinical nurse specialist (CNS) team

Telephone: **023 8120 8765**

Email: **gynaecologysupport@uhs.nhs.uk**

Macmillan support worker (MSW)

Telephone: **07775 691993**

We are available Monday to Friday during office hours. Outside of these times, please leave a brief message including your contact telephone number on our answerphone. A member of the CNS team or a Macmillan support worker (MSW) will call you back within one working day. They will discuss the nature of your concern with you and, if necessary, arrange a clinic appointment within two weeks. Your GP can also use this number to contact us if he or she feels you need to be seen by the gynaecology team.

Your personal details

Name:

Hospital number:

Diagnosis:

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Date of diagnosis:

Surgical consultant:

Oncology consultant:

Macmillan gynaecology oncology nurse specialist team: **023 8120 8765**

Macmillan support worker: **07775 691993**

Date of health and wellbeing workshop:

Annual surveillance due:

Recovering from your surgery

There is very good evidence that encouraging patients to return to normal levels of activity as quickly as possible after surgery 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 timeline. 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 (laparoscopy) you should be able to do most things after around two or three weeks.

If you have had an abdominal incision (open surgery), recovery can take a little longer. By six weeks many women are almost back to normal.

Further reading:

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

Recovering from 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 treatment has finished.

If you have a skin reaction, this should resolve and completely heal four to six weeks after radiotherapy.

Many patients feel tired both during and after radiotherapy. This can be 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 sunburnt. You should cover the treated area as it may be more sensitive. Use high factor sun cream – at least factor 30. Once the skin reaction has settled you can return to activities such as swimming. This is normally possible within a month of finishing treatment.

Possible 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. Your CNS or specialist radiographer will have advised you how to use vaginal dilators (from about two to six weeks after radiotherapy has ended). Please refer to the Macmillan "Pelvic radiotherapy in women: possible late effects" booklet.

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, however, may need to make some changes to their diet and lifestyle to be able to deal with the effects.

For a small number of women, the changes may be difficult to cope with. The changes may mean that they have to restrict their activities, reduce or give up work, or limit socialising because of needing to stay close to a toilet. Please speak with your CNS or clinical oncologist if you have any concerns. If necessary, a referral can be made to a continence advisor, lymphoedema specialist or psycho-sexual counsellor. The Bladder and Bowel Foundation can also give support (details at the end of this booklet).

Further reading:

- [Understanding radiotherapy](#)
- [Pelvic radiotherapy in women: possible late effects](#)
- [Sexuality and cancer – available from Macmillan Cancer Support \[www.macmillan.org.uk\]\(http://www.macmillan.org.uk\)](#)

Recovering from your chemotherapy

If you have any concerns about side effects following chemotherapy please contact the CNS team for advice.

Further reading:

- [Understanding chemotherapy – available from Macmillan Cancer Support www.macmillan.org.uk](http://www.macmillan.org.uk)

Managing menopausal symptoms

Most women diagnosed with endometrial cancer will have already gone through the menopause. In those women who have not yet gone through the menopause, surgery for endometrial cancer usually includes removing the ovaries, which will lead to a surgically-induced 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 endometrial cancer. However, if symptoms are affecting your quality of life, the risks and benefits of starting HRT can be discussed with your consultant and/or CNS.

Vaginal dryness

If you are suffering from vaginal dryness, vaginal lubricants/moisturisers such as Sylk, Yes or Replens MD 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 or GP.

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 endometrial cancer. Some women have found evening primrose

oil helpful, however, there is no scientific evidence to prove this.

Additional help

Do tell your CNS 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. It may be possible for you to be referred to a doctor who specialises in treatment-induced menopause.

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. Many patients will also find that it takes rather longer than they expect to recover fully from their treatment.

Emotional support

The amount and type of emotional support required after a diagnosis of endometrial cancer varies between women. Some women prefer not to talk things through, while others find it helpful to speak about their experience. There is no right or wrong way, just what works for you. Please contact your CNS for emotional support if needed. Alternatively you can self-refer to the Macmillan support centre or Wessex Cancer Trust for counselling.

Resuming sexual activity

Sometimes women 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, please contact your CNS team or MSW.

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

Returning to work

You can return to work whenever you feel ready to do so. All jobs are different so it's difficult to be more specific. Some women find they can work throughout their 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 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?

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. Please phone the Macmillan Citizen's Advice Bureau (CAB) on 0344 847 7727.

Further reading:

- [Help with the cost of cancer](#) – available from Macmillan Cancer Support www.macmillan.org.uk

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.

Diet

Enjoying a healthy diet, maintaining a healthy weight and doing a moderate amount 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 and doing 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 at least 5 portions of fruit and vegetables per day
- eat plenty of foods rich in fibre and starch, and whole grains
- avoid eating too much fatty food especially saturated or animal fats
- restrict sugary food and drinks.

These guidelines are also suitable for people who have not had a cancer diagnosis and can also 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 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 the NHS website: www.nhs.uk

Further reading:

- [Diet and cancer – Macmillan Cancer Support](http://www.macmillan.org.uk)
- [Lifestyle and cancer – World Cancer Research Fund](http://www.wcrf-uk.org)

Alcohol

The Department of Health recommend a maximum of 14 units of alcohol per week (a unit of alcohol equals a small glass of wine or half a pint of beer). Aim to have at least two alcohol free days per week.

Travelling abroad

Once you have completed your treatment, there is no reason for you not to travel abroad. Sometimes patients who have been treated for cancer can have difficulties getting travel insurance. More information is available in the Macmillan booklet 'Travel and cancer'. The Macmillan website has an online community forum where patients exchange suggestions about travel insurance.

- www.macmillan.org.uk

Dealing with worries about endometrial 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 endometrial cancer will never return. Unfortunately, we can never make this promise to any patient.

What is the chance of my cancer returning?

The risk that endometrial cancer will come back is different for every patient. However, by having the treatment recommended by your surgeon and oncologist you have minimised your risk of having any further problems from endometrial 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 endometrial 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 cancer will return – what can I do?

It is entirely natural to feel anxious that your 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 may benefit from individual or family counselling. This may be available from your GP, the Wessex Cancer Trust or Macmillan Cancer support centre at University Hospital Southampton.

How long does PTFU last?

You will follow the PTFU programme for five years, after which you will be discharged. You and your GP will be sent a letter informing you of this.

After five years, if you have any concerns, you should contact your GP.

Further information and useful contacts

Local support contacts

Hampshire Macmillan Citizens Advice Service

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

Telephone: **0344 847 7727**

Jane Scarth House Cancer Support Centre

This is a local charity whose services, provided in a non-medical setting, range from befriending and counselling to meditation and other complimentary therapies.

39 The Hundred, Romsey, SO51 8GE

Telephone: **01794 830374**

www.janescarthhouse.co.uk

Portsmouth Macmillan Centre

Offers information and support to patients, their families and professionals on many aspects of living with cancer and its treatments.

Queen Alexandra Hospital, Portsmouth

Telephone: **023 9228 3323**

www.porthosp.nhs.uk/macmillan

Southampton Macmillan Cancer Information and Support Centre

Providing information, counselling and complimentary therapies.

B level, Southampton General Hospital.

Telephone: **023 8120 6037**

www.uhs.nhs.uk/macmillan

Wessex Cancer Trust (WCT)

Local charity providing information, counselling and complementary therapies. WCT have support centres in Chandler's Ford, Hythe, Newport, Salisbury and Bournemouth. Provide non-clinical support for cancer patients and their families.

Telephone: **023 8067 2200**

www.wessexcancer.org

National support contacts

Bladder and Bowel Community

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

Telephone: **01926 357220**

www.bladderandbowel.org

Cancer Research UK

Cancer research and awareness charity.

Telephone: **0808 800 4040**

www.cancerresearchuk.org

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

The Eve Appeal

A national appeal aiming to improve awareness and funding of research into gynaecological cancers.

www.eveappeal.org.uk

The Lymphoedema support network

National UK charity which provides information and support to people with lymphoedema.

Telephone: **0207 351 4480**

www.lymphoedema.org

Some of the sections in this leaflet have been adapted with permission from information by Macmillan Cancer Support.

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Tremona Road
Southampton
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SO16 6YD

Main switchboard: **023 80 777 2222**

Gynae-oncology clinical nurse specialist (CNS) team: **023 8120 8765**

For a translation of this document, or a version in another format such as easy read, large print, Braille or audio, please telephone **023 8120 4688**.

For help preparing for your visit, arranging an interpreter or accessing the hospital please visit: **www.uhs.nhs.uk/additionalneeds**

www.uhs.nhs.uk

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