

Self-directed follow-up after treatment for cancer of the womb: patient guide

This leaflet is for women who have received treatment for womb/endometrial cancer. It explains how follow-up appointments are changing. Feel free to discuss any questions or concerns with your nurse on: 0118 322 8195

What is changing?

Traditionally patients who have completed their treatment for womb cancer are reviewed by their surgeon or oncologist at regular intervals in a follow-up clinic for up to five years.

For some patients, these planned clinic visits are valuable and reassuring, although for many patients travelling to hospital for such visits can be stressful and not always necessary unless there is a particular concern they wish to discuss.

Research into how patients who have had a cancer are followed up, has confirmed that having face to face clinic reviews does not prevent the cancer from returning and therefore does not increase life expectancy.

How does self-directed follow-up work?

'Patient self-directed follow-up' enables you to arrange and attend a follow-up appointment when needed if you have any concerns. You will not need to attend for regular planned reviews in the clinic but would simply make contact with your clinical nurse specialist or consultant secretary to arrange a review in clinic or a telephone consultation. We would endeavour to arrange such an appointment as soon as possible – typically within 2 weeks.

After five years of treatment completion, if you had any concerns or worries which could be related to your cancer we would then advise you to go back and see your GP.

What next?

The following pages will outline relevant information about your individual cancer, the treatment you have received and any on-going treatment plan. It also explains how and when to contact your team for advice or to arrange follow-up and includes further useful information and contacts which you may find helpful.

When should I contact my hospital team?

You should arrange a review at the hospital by a member of the Gynae Cancer Team if you have any new symptoms that you are worried about which could be related to your previous womb cancer or your cancer treatment or you feel could represent a recurrence of your cancer.

If you are unable to speak with someone directly, please leave a brief message with your name, date of birth and contact number. We will contact you within two working days, either by a clinical nurse specialist or the appropriate secretary. They can arrange an appointment within two weeks from your telephone call.

Your GP can also use these numbers to contact our team if they feel you need to be seen in our clinic for a face to face review.

What symptoms should I be reporting to my Gynae Cancer Team?

- New vaginal bleeding or vaginal discharge.
- Abdominal pain which is on-going or constant.
- Unexpected weight loss or loss of your appetite.
- Persistent bowel habit changes (new diarrhoea or constipation).
- Persistent problems with passing urine.
- Any other persistent new symptoms which cannot be explained.

Please remember that there are other health reasons not related to your previous cancer which could cause some of these symptoms.

Cancer rehabilitation: what is it?

Cancer rehabilitation supports people to live well with and beyond cancer, using a range of tools and opportunities that can enhance your recovery and improve your ability to 'tackle tomorrow'. It is available to anyone who has received cancer care at the Royal Berkshire Hospital and is run by Macmillan Cancer Support and the Royal Berkshire NHS Foundation Trust.

How can it help you?

There are a range of services that are available for you to use when you need them, including:

- **Physical activity:** Being more physically active can help you cope with and recover from the negative effects of cancer and treatment, such as tiredness, being less socially active, lack of stamina and confidence.
- **Psychological support:** Living with and after a cancer diagnosis can be difficult and lead to many emotions, such as sadness and depression, loneliness, worry, fear and anxiety, anger and frustration. This is perfectly normal, but if these emotions become overwhelming then professional support can help. Your family or those significant to you may also be able to access this support if it is helpful to them.
- **Practical issues:** Cancer can impact on many practical issues, such as the caring responsibilities you may have, work or education, as well as having a huge impact on finances. Advice from professionals can help support you and minimise this impact.
- **Self-management and education:** Being informed enables you to understand your condition and empowers you to manage it more effectively. We provide educational courses to suit your needs.

- **Social peer support:** Sharing your experience with others who have been through something similar can be really positive and uplifting. We can inform you of support groups and other activities available locally.

To help you look at moving forward, we think it's important that these services are linked between the hospital and community, so many of the activities take place in leisure or community centres, supported by trained cancer professionals.

Designed for you

We offer a flexible service, as we recognise there may be times when the psychological and physical effects of cancer are having a bigger impact on you and other times when you feel you are able to continue with little or no support.

What do we offer?

We run monthly Macmillan 'Take Control' workshops for patients and families. This is a short day self-management course and will cover topics such as:

- Sleep problems
- Healthy eating and diet
- Physical activity and exercise
- Stress and fatigue
- Fear of the future
- Goal setting

How do I get more information about cancer rehabilitation?

Please email cancer.rehabilitation@nhs.net or call **01344 662909** and leave a voicemail if you would like any more information, or to refer yourself in to the service. One of the team will get back to you. You can also ask your consultant, GP or specialist nurse to refer you in to the service using the above contact details.

Useful contacts

- **Macmillan:** General information on cancer, cancer treatments and physical, emotional and financial support. **0808 808 00 00** (7days a week 9am-5pm) <https://www.macmillan.org.uk/>
- **Berkshire Cancer Centre Macmillan Cancer Information Centre:** Information and support services for anyone affected by cancer. **0118 322 8700**
macmillan.information@royalberkshire.nhs.uk
- **The Eve Appeal:** To contact our nurse-led information service about any questions related to gynaecological health, **0808 802 0019** – which is free to call from landlines and mobile phones <https://eveappeal.org.uk/>

- **Gynae Cancer Coffee and Chat Support Group:** First Wednesday of the month 10.30am-12.00. Royal Berkshire Hospital Trust Education Centre (Craven Road). For more information contact Lisa Clarke, Clinical Nurse Specialist **0118 322 8195** or by email at Lisa.clarke@royalberkshire.nhs.uk

To find out more about our Trust visit www.royalberkshire.nhs.uk

Please ask if you need this information in another language or format.

L Clarke, BCC Gynae Cancer Team, June 2020

Reviewed: December 2022

Next review due: December 2024