



Patient initiated follow-up for women with endometrial cancer

Your doctor has recommended patient initiated follow-up for you after your treatment for endometrial (uterine or womb) cancer. This information sheet explains what patient initiated follow-up involves. If you have any further questions about the follow-up or information included in this leaflet, please speak to your healthcare team.

What is patient initiated follow-up?

Patient initiated follow-up is a form of follow-up used after endometrial cancer treatment has finished. It will continue for three years after you completed your treatment and will replace routine hospital appointments. This means that you will not have to come to hospital when you are feeling well and are not experiencing any symptoms. Instead, you will be able to contact your specialist team and arrange to see them only if you need to.

Patient initiated follow-up is used in many hospitals across the UK, although it may be referred to differently in other places.

What are the benefits of patient initiated follow-up?

The main advantage is that you will not have to attend routine follow-up appointments in the hospital. Many patients have told us that these appointments often make them anxious. They are also likely to put off reporting any worrying symptoms if a routine clinic appointment is not 'too far away'.

Are there any risks?

Some people worry that not having regular follow-up appointments at the hospital may cause their cancer to go unnoticed if it comes back. However, it has been proven that endometrial cancer recurrence is unlikely to be picked up by clinical examination alone when a patient has no worrying symptoms. In fact, patients tend to identify most recurrences themselves in between appointments. If there are any symptoms you are worried about, or if you have any concerns you would like to discuss, you will be able to contact your clinical nurse specialist (CNS).

How will it work for me?

Once you have finished your treatment for endometrial cancer, you will have a consultation with your surgeon and an 'end of treatment' clinic appointment with your CNS. During these appointments, your healthcare team will talk to you about:

- Your diagnosis
- Your treatment and the possible side effects you might experience
- The signs and symptoms to look out for and report
- How to contact the team
- The process the team will follow if you need to come back to the clinic at any time in the future
- How the team will keep your GP informed throughout your follow-up.



What are the signs and symptoms to look out for?

You should report the following symptoms to your CNS straight away:

- Vaginal bleeding
- Worsening or persistent abdominal (tummy) pain
- Change in bowel or bladder habits
- Unexplained weight loss or loss of appetite
- New shortness of breath or chest pain
- Persistent bone pain.

How do I contact the team?

Please contact your CNS on **020 7288 5161 (07920 237 346)** if:

- You develop any new signs or symptoms
- You have any concerns about managing your health and wellbeing following your treatment
- Any of your original signs or symptoms return.

This helpline is monitored between 9am and 5pm, Monday to Friday. If your CNS cannot take your call, please leave a voicemail message and one of the team members will call you back. This will either be within 24 hours or the next working day.

Alternatively, please call the Women's Health Team Secretaries on **020 7288 5407**.

What are the alternatives to patient initiated follow-up?

If you have specific concerns or health-related issues that make patient initiated follow-up unsuitable for you, you can have traditional follow-up appointments in the clinic. Your doctor and CNS will discuss this with you in more detail.

Will I need to have any regular tests?

Most patients will not need any routine tests or scans related to their cancer or cancer treatment. But we will advise you and your GP if there are any regular tests you may need. Your GP will then arrange them as needed. **You will not need smear tests.**

Patient advice and liaison service (PALS)

If you have a compliment, complaint or concern please contact our PALS team on 020 7288 5551 or whh-tr.PALS@nhs.net

If you need a large print, audio or translated copy of this leaflet please email whh-tr.patient-information@nhs.net. We will try our best to meet your needs.

Twitter.com/WhitHealth
Facebook.com/WhittingtonHealth

Whittington Health NHS Trust
Magdala Avenue
London
N19 5NF
Phone: 020 7272 3070
www.whittington.nhs.uk

Date published: 05/08/2022
Review date: 05/08/2024
Ref: ACW/WH/PIFUWE/01

© Whittington Health
Please recycle

