

## Cancer of the lining of the womb, low risk – Patient-Initiated Follow-up

Patient initiated follow-up (PIFU) is a method of follow-up that enables you to manage your own follow-up appointments. This will provide you with direct access to a clinician tailored to your specific needs if you develop new symptoms.

Based on the stage of cancer of the womb that you have been diagnosed with (low risk endometrial cancer), evidence suggests that there is no added benefit from routine follow-up appointments. In fact, most of the recurrences (cancer coming back) are recognised when patients report symptoms. Patient-initiated follow-up will enable you to take control of your own care and get help when you need. It also offers several additional benefits like reducing unnecessary hospital appointments and spending less time travelling to hospitals. Through patient-initiated follow-up, we aim to respond to your needs as quickly as possible while avoiding unnecessary 'routine' hospital appointments.

You have been assessed by a team of expert doctors including your own Gynaecology consultant and found to be suitable for patient-initiated follow-up. This information below tells you when you need to seek medical advice and what happens then.

### When should I contact the team for advice?

You should contact the Gynae Oncology Clinical Nurse Specialist (CNS) team if you experience any of the following symptoms:

- Vaginal bleeding or discharge
- Persistent problems passing urine or blood in the urine, if your GP has already ruled out a urine infection (UTI).
- Changes in bowel habits – new or alternating constipation or diarrhoea.
- Unexplained weight loss
- Tummy pain
- Pelvic pain

You will be given a trigger card to help you decide when you should contact us; the card is designed to fit in a purse or wallet so that you can conveniently refer to it. The trigger card highlights any symptoms that you should look out for and how to contact the PIFU team for help. These problems may have several different causes, but it is always advisable to contact us for advice.

### Who do I contact if I have concerns?

If you develop any worrying symptoms or have any cancer related concerns, please contact your **Clinical Nurse Specialist (CNS)** Monday to Friday, 9am to 4pm.

Telephone: 01296 838240

The clinical nurse specialist will then phone you back to discuss your concerns.

## What happens after I contact my team for advice?

The clinical nurse specialist will discuss your concerns with you and together you will decide whether you need further investigations or referral for examination. It might be that further investigations can be done by your GP. It might be that you need blood tests or scans, or an appointment with your specialist consultant for an examination. Often you may find that reassurance is all that is needed. If further tests are required, the aim will be to do these within two weeks.

## General thoughts and feeling about Patient-Initiated Follow-Up

You may have mixed feelings about no longer needing to be seen regularly by your cancer team. Some women feel relieved that they can now start getting their lives back to normal; others may be concerned about what could happen in the future and are anxious about losing contact with their specialist team.

These feelings are all normal. This pathway enables you to have direct and quick access to a member of your specialist team if you need their help or expertise.

## You may find these websites useful:

- Early Menopause - [www.daisynetwork.org](http://www.daisynetwork.org)
- The Eve Appeal - [www.eveappeal.org.uk](http://www.eveappeal.org.uk)
- Macmillan - <https://www.macmillan.org.uk/>

## Supportive programmes for after treatment:

- Buckinghamshire Healthcare NHS Trust – Cancer Care and Haematology, HOPE course, Take Control course
- Hummingbird Centre, Bicester
- Look Good Feel Better (National)
- South Bucks Hospice

## Support Groups:

- Buckinghamshire Healthcare NHS Trust – Cancer Care and Haematology, Lavender girls. Wycombe and Stoke Mandeville hospitals  
Tel: 01296 838240
- Maggie's Oxford, Below the Belt  
Tel: 01865 751882 Email: [oxford@maggiescentres.org](mailto:oxford@maggiescentres.org)

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Please remember that this leaflet is intended as general information only. We aim to make the information as up to date and accurate as possible, but please note that it is subject to change. Please therefore always check specific advice on any concerns you may have with your doctor.

## How can I help reduce healthcare associated infections?

Keeping your hands clean is an effective way of preventing the spread of infections. Please follow our infection prevention and control guidelines available on our website.

## Patient Advice Sheet

If you would like a copy of this information on audiotape, in large print or translated, please call the Patient Advice Liaison Service on 01296 831120 or email [bht.pals@nhs.net](mailto:bht.pals@nhs.net)