



## **PATIENT INFORMATION LEAFLET**

# **PATIENT INITIATED FOLLOW UP (PIFU) / PATIENT STRATIFIED FOLLOW UP (PSFU) FOR GYNAECOLOGY ONCOLOGY CANCERS**

This leaflet aims to explain the next steps now that your treatment is completed, and it has been agreed by yourself and your cancer team that routine hospital appointments are no longer required.

We understand that you may worry stopping regular follow up appointments may cause a cancer recurrence to go unnoticed. However, evidence suggests that regular follow up appointments do not prevent cancer from returning and patients tend to identify most recurrences themselves. The risk of low grade/low stage, Granulosa Cell Ovarian Tumour, Endometrial Cancer or Cervical Cancer returning varies between individuals. Please be reassured your personal risk has already been reduced by following the treatment plan your medical team have recommended.

The aim of PIFU is to put you in control and allows you to contact us if you have any symptoms, worries or concerns.

Our cancer care coordinator will also arrange to call you around 3 months after initiating your Patient initiated follow up just to check if you have any concerns you wish to discuss, and sign post you to any relevant services.

If there is a clinical need for you to see a doctor or a nurse an appointment will be arranged for you, or the team may advise you to see your GP.

## **WHEN TO CONTACT YOUR GP OR HOSPITAL TEAM?**

### **Patient Initiated Follow Up (PIFU) after completing treatment for cancer of the uterus (womb) or cervical cancer:**

As you are on Patient Initiated Follow Up, you will receive yearly letters that include a list of what symptoms to look out for and our contact details if you get any of the following symptoms:

- Vaginal bleeding (spotting or heavy, red, or brown in colour), contact your specialist nurse as soon as possible
- Bleeding after intercourse – contact your specialist nurse

**If you experience any of the problems listed below for more than two weeks you should contact your G.P. or hospital team:**

- Persistent vaginal discharge that's not fresh or old blood

- Abdominal pain and/or bloating
- Pelvic pain
- Back pain
- Unexplained weight loss
- Loss of appetite
- Feeling very tired
- Leg swelling (lymphoedema)
- Persistent change in bowel habit e.g. ongoing constipation or diarrhoea
- Persistent problems passing urine

There are a number of reasons these symptoms can occur, but it is always sensible to speak to a healthcare professional.

### **Patient Stratified follow up (PSFU) after completing treatment for a low grade & stage Ovarian Cancer or a Granulosa cell tumour:**

As you are on the Patient Stratified Follow Up, you will receive yearly letters that include a list of symptoms to look out for and a reminder letter to have continued blood tests:

- Initially 3 monthly till 2 years
- 6 monthly till 5 years
- If you've had a Granulosa Cell Tumour, you will continue having yearly blood tests for a total of 10 years.

**If you experience any of the problems listed below for more than two weeks you should contact your G.P. or hospital team:**

- Abdominal/pelvic pain
- Feeling bloated
- Feeling full quickly when you eat
- Nausea/vomiting
- Loss of appetite
- Vaginal discharge/bleeding
- Feeling excessively tired
- Unexplained weight changes (loss or gain)
- Change in bowel habit
- Change in bladder habit
- Shortness of breath/persistent cough
- Leg swelling (lymphoedema)

## **HOW TO BOOK AN APPOINTMENT IF YOU HAVE CONCERNS?**

If you develop any worrying symptoms or have any cancer related concerns, you can contact your specialist nurse who can discuss your concerns with you and together help decide if you need to come to clinic for an appointment. Please see the contact details at the bottom of this leaflet.

## YOUR THOUGHTS AND FEELINGS ABOUT INITIATED FOLLOW UP

Everyone has different feelings when they no longer need to be seen regularly by their cancer team. Some individuals 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 perfectly normal but please be reassured your cancer team will always be available for you if you need their help and expertise.

## CONTACT DETAILS

Macmillan Gynae Oncology Nurse Specialists 0161 276 6394



(Monday to Friday 09.00am to 5.00pm)

**If you require any further information or clarification, including clarification of terminology, please do not hesitate to talk to one of the doctors or nurses, who will be happy to discuss your concerns with you.**