

# Patient-initiated follow-up

Information and advice for patients

## Gynae-oncology

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This information explains ways in which you can continue to access support and advice about your health now that you have been discharged from Hospital follow-up appointments. If you have any concerns or questions that are not answered in this leaflet please speak to your Clinical Nurse Specialist.

### What is patient initiated follow-up

Patient initiated follow-up puts you in control of any further follow-up appointments you have. Instead of being offered regular clinic visits, you can make an appointment to see us if you have any worries or concerns. You will be given 'open access' to our service, which means that if you ever feel worried that you have a problem that may be related to your previous cancer or treatment, you can contact the Clinical Nurse Specialists. They will discuss and assess your concerns on the phone and make an appropriate appointment for you to be seen by the Consultant.

The reason we offer follow-up this way is because having regular outpatient follow-up does not help prevent cancer returning or identify any new problems and many patients find the follow-up visits to the Hospital cause anxiety.

Your Clinical Nurse Specialist will still be available for you to contact for specialist advice, support and information.

### Symptoms you should report.

The following symptoms may be related to other conditions but if you experience any of them you should call the team to arrange a follow-up appointment so that they can be checked.

#### If you had cancer of the ovary

(Including borderline ovarian tumours)

- Abdominal (tummy) swelling or persistent bloating
- Change in bowel habits
- Change in appetite
- Vaginal bleeding
- Passing urine more frequently
- Abdominal or pelvic pain that does not go away
- Unexplained weight loss
- Pain under the ribcage

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### If you had cancer of the womb or cervix

- Unexplained vaginal bleeding
- An offensive smelling vaginal discharge
- Bleeding after sex
- Leaking of urine or faeces
- Pelvic, back or bone pain
- Shortness of breath
- Unexplained swelling of either or both legs

### If you had cancer of the vulva

- A new swelling or ulcer in the area previously treated
- New pain that does not go away
- Soreness or severe itching in the area
- A change in the colour or shape of the remaining skin
- New swelling or pain in the groin
- Unexplained swelling of either leg
- Bleeding from the front passage or the vulva
- Difficulty passing urine or having your bowels open

## Ongoing support

Adjusting to a cancer diagnosis and having treatment can cause ongoing concerns. Some women will have different feelings when they no longer need to be seen regularly by their medical team. Some women feel relieved that they can now start adjusting to their new lives; others may be concerned about what could happen in the future and are anxious about losing contact with the hospital. You will continue to have open access to the Clinical Nurse Specialists for ongoing support and be invited to a well-being event following completion of your treatment.

## Well-being event

You will be invited to attend a well-being event by the team. The event provides advice and support sessions to live as healthily and actively as possible during or after your treatment has been completed.

## Further information and support available

**Macmillan Cancer Support**

0808 808 0000

[www.macmillan.org.uk](http://www.macmillan.org.uk)

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### Ovacome (ovarian cancer support network)

0800 008 7054

[www.ovacome.org.uk](http://www.ovacome.org.uk)

### Target ovarian cancer

020 7923 5475

[www.targetovariancancer.org.uk](http://www.targetovariancancer.org.uk)

### Jo's cervical cancer Trust

0808 802 8000

<https://www.jostrust.org.uk/>

### Vulva awareness campaign

[www.vaco.co.uk](http://www.vaco.co.uk)

(All websites accessed 09 March 2022)

## Contact Us

### Macmillan Gynae-Oncology Clinical Nurse Specialist team

0121 507 5511

Alternatively you can contact the hospital switchboard on 0121 554 3801 and ask them to bleep the team on 5036

## Sources used in this leaflet

European Society of Gynaecological Oncology (ESGO). (No date). European Society of Gynaecological Oncology (ESGO) guidelines and quality indicators. Available at: <https://guidelines.esgo.org/> (Accessed 09 March 2022).

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