

**Patient
Information**

Patient-initiated follow-up after a gynaecology cancer diagnosis

Introduction

This leaflet gives you information about how to get support and advice now that you have been discharged from the hospital follow-up routine.

What is patient initiated follow-up?

Now that your treatment is complete you and your doctor have agreed that you do not need to come to the hospital for routine appointments. Therefore, you will not be seen regularly at the hospital but your Clinical Nurse Specialist is still available to contact if you need them, as is your GP.

Instead, you will now take control of your care. You can contact us to arrange an appointment quickly if you have any worries, problems or concerns related to your cancer.

Routine follow-up appointments do not identify new problems relating to your cancer diagnosis; but reporting signs, symptoms and concerns early on means that they can be addressed a lot quicker and reduce any anxiety.

Please be reassured that if you need to be seen by your Clinical Nurse Specialist or doctor, an appointment can be arranged quickly or the team may advise you to seek advice from your GP.

When you should contact your GP or hospital team

If you get a sudden start of vaginal bleeding or unusual vaginal discharge (offensive in smell or unusual colour), contact your Clinical Nurse Specialist as soon as possible.

If you get any of the symptoms or problems listed below for more than 2 weeks, contact your GP or Clinical Nurse Specialist.

Reference No.

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Department

Gynaecology

Review due

January 2028

Patient Information

If you had ovarian, fallopian tube or primary peritoneal cancer:

- Swelling of the abdomen (tummy) or persistent bloating
- Feeling full when you eat
- Abdominal or pelvic pain that does not go away
- Change in bowel habits
- Urine incontinence or passing urine very frequently
- Change in appetite
- Unexplained weight loss
- Nausea/vomiting

If you had cancer of the womb (uterus), endometrium or cervix:

- Unexplained vaginal bleeding
- Bleeding after sex
- Unusual vaginal discharge (offensive in smell or unusual colour)
- Leakage of urine or faeces
- Pain in the pelvis, back or bones
- Shortness of breath or persistent cough
- Leg swelling (lymphoedema)

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

Your feelings

Every patient will feel different when they no longer have regular follow-ups with their medical team. Some women feel relieved that they can get back to normal, but others may be anxious at the thought of losing contact with the hospital.

Most women worry about their cancer coming back and this is normal. If you feel that you cannot move forward with your life, then speak to your Clinical Nurse Specialist or GP who can get you extra support. You may be referred to Maggie's 'Big Op Support Group'.

**Patient
Information****Maggie's - 'Big Op Support Group'**

The 'Big Op Support Group' is run on a monthly basis on the third Tuesday of the month at the Maggie's Centre, Cheltenham by the Gynaecology Clinical Nurse Specialists and staff at Maggie's.

If you are finding it difficult to 'move on' after your treatment you may find attending this group useful. It is a supportive, non-clinical and safe environment where you can talk about your concerns and fears with the support of women who have had a similar journey.

Maggie's Cheltenham

Tel: 01242 250 611

Monday to Friday, 9:00am to 5:00pm

Contact information

To arrange a review, please use the contact numbers below:

Gynaecology Surgical Clinical Administration Team

Tel: 0300 422 4464

Monday to Friday, 8:00am to 4:00pm

Oncology Secretary

Tel: 0300 422 4925

Monday to Friday, 8:00am to 4:00pm

Gynaecological Cancer Nurse Specialists

Tel: 0300 422 4047 or

Tel: 0300 422 3181

Monday to Friday, 8:30am to 4:30pm

If we cannot take your call, please leave a short message with your name, date of birth and contact number. Someone will get back to you as soon as possible.

The table on the next page gives you information about your cancer diagnosis, treatment and medical team.

**Patient
Information****Your personal details**

Name:

NHS number:

Diagnosis and date:

Surgical treatment:

Date(s) of surgery:

Radiotherapy treatment:

Date(s) of radiotherapy:

Medical treatment:

Date(s) of medical treatment:

Surgical consultant:

Oncology consultant:

Clinical Nurse Specialist:

Individual treatment plan:

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Further information

Gloucestershire Domestic Abuse Support Service (GDASS)

This is a county-wide service offering a variety of support programmes for women and men over 16 years old who are experiencing domestic abuse.

Tel: 01452 726 570

Monday to Friday, 9:00am to 5:00pm

Domestic Violence Helpline

Tel: 0808 2000 247 (24 hours)

Email: support@gdass.org.uk

Website: www.gdass.org.uk

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Making a choice

Shared Decision Making

If you are asked to make a choice, you may have lots of questions that you want to ask. You may also want to talk over your options with your family or friends. It can help to write a list of the questions you want answered and take it to your appointment.



Ask 3 Questions

To begin with, try to make sure you get the answers to three key questions if you are asked to make a choice about your healthcare.

1. What are my options?
2. What are the pros and cons of each option for me?
3. How do I get support to help me make a decision that is right for me?

These resources have been adapted with kind permission from the MAGIC Programme, supported by the Health Foundation

* Ask 3 Questions is based on Shepherd HL, et al. Three questions that patients can ask to improve the quality of information physicians give about treatment options: A cross-over trial. Patient Education and Counselling, 2011;84: 379-85



<https://aqua.nhs.uk/resources/shared-decision-making-case-studies/>