A guide for women on shared follow-up and survivorship care

Why is follow-up and survivorship care important?

After treatment for low-risk endometrial cancer, it is important to have follow-up visits to:
- check whether the cancer has come back
- monitor and address any side effects of treatment
- receive practical and emotional support.

Follow-up care involves your primary care team (General Practitioner (GP) and primary health care nurse) and the specialist multidisciplinary gynaecological cancer team (specialist team).

What is shared follow-up and survivorship care?

When your follow-up care is shared between your specialist team and your primary care team, this is known as shared follow-up and survivorship care.

Allied health professionals, such as dietitians, psychologists and others, may also be involved in your care. However, your specialist team and primary care team will coordinate your follow-up care for low-risk endometrial cancer.

What are the benefits of shared follow-up and survivorship care?

- **Safe and effective**
  - Follow-up care that is carried out by your primary care team is a safe and effective alternative to follow-up care that is carried out by your specialist team. Follow-up care with your GP can also provide continuous quality care over time.

- **Convenient and easy to access**
  - Shared follow-up care may be more convenient for you as it may be easier to get access to your GP than your specialist team.

- **Addresses multiple care needs**
  - You may benefit from the fact that your GP will oversee all of your health issues rather than just one aspect of your care.

What is a Shared Care Plan?

A Shared Care Plan contains information about your diagnosis, treatment and follow-up and survivorship care. A Shared Care Plan helps your specialist team and primary care team to coordinate and manage your follow-up care. Your specialist team and GP will work with you to develop this plan.
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What should I expect in shared follow-up and survivorship care?

- Your specialist team will support and communicate with your GP about your follow-up care.
- Most of your follow-up visits will be with your GP rather than with your specialist team.
- If required, your GP will arrange a consultation for you with your specialist team at any time during your follow-up care.

As part of your shared follow-up care, you will also be provided with resources to support your health and wellbeing. This will include information on what to expect after treatment, symptoms of endometrial cancer returning, and support for living well. This is known as ‘survivorship care’.

Roles and responsibilities

It is important for you, your specialist team and your GP to take an active role in shared follow-up care. It is also important that everyone’s roles and responsibilities are discussed and agreed to before starting your shared follow-up care.

The table below provides an overview of the roles and responsibilities involved in shared follow-up care.

<table>
<thead>
<tr>
<th>YOUR ROLE</th>
<th>SPECIALIST TEAM</th>
<th>GP</th>
</tr>
</thead>
<tbody>
<tr>
<td>– talk openly with your specialist team and GP, including discussing your specific care needs</td>
<td>– contacts and provides your GP with a detailed treatment summary</td>
<td>– provides care and manages the effects of treatment for endometrial cancer</td>
</tr>
<tr>
<td>– develop your Shared Care Plan together with your specialist team and GP</td>
<td>– records the results of your follow-up care and sends the updated results to your GP</td>
<td>– ensures a detailed treatment summary has been received from your specialist team</td>
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<tr>
<td>– bring your Shared Care Plan with you when you visit your specialist team or GP</td>
<td>– provides consultations with you and your GP, when requested.</td>
<td>– records your follow-up care results and sends updated results to your specialist team</td>
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<tr>
<td>– watch for signs and symptoms that might mean a return of cancer</td>
<td></td>
<td>– manages a range of other health issues and provides information on prevention and living well</td>
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<tr>
<td>– take steps to maintain a healthy lifestyle.</td>
<td></td>
<td>– refers you to your specialist team when required</td>
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<td></td>
<td></td>
<td>– provides support and when needed, referral to allied health professionals (such as psychologists and dietitians).</td>
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What will happen during my follow-up visits?

Although your GP and your specialist team share responsibility for your follow-up care, in most instances you will see your GP.

**During these visits, you will discuss:**

- symptoms that may indicate your cancer has returned and how to identify these symptoms
- side effects that you may experience as a result of your treatment for endometrial cancer
- your individual care and support needs
- your physical, social and emotional wellbeing.

Your GP will take a detailed medical history, conduct a physical examination, including a pelvic examination, and ask questions about your emotional health.

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How often will the follow-up visits be?

How often you need to attend follow-up visits will be based on your individual situation. You will be provided with a follow-up care schedule, which will outline who you will see for each visit and when. You should speak with your specialist team or primary care team about making these appointments.

The suggested timing for follow-up visits is:

<table>
<thead>
<tr>
<th>YEARS 1-2</th>
<th>YEAR 3</th>
<th>YEARS 4-5</th>
</tr>
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<tbody>
<tr>
<td>Every 3–6 months</td>
<td>Every 6–12 months</td>
<td>Every 12 months</td>
</tr>
</tbody>
</table>

Symptoms to look out for that might mean a return of endometrial cancer

Sometimes endometrial cancer can come back after treatment (known as recurrence). This is why it is important that you are aware of the symptoms of cancer returning and that you attend regular follow-up appointments with your primary care team and/or specialist team.

Symptoms of endometrial cancer returning include:

- vaginal bleeding or discharge
- new, constant and worsening pain in the pelvic area, stomach area or back of the legs
- changes in bowel habits
- difficulty or pain when urinating
- nausea, vomiting or bloating
- persistent cough or shortness of breath
- unexplained weight loss.

If you notice any new or unusual symptoms between follow-up visits, do not wait until your next scheduled appointment.

See your GP as soon as possible so that the cause of your symptom can be explored.