Shared Decision-Making

A guide for people living with endometrial cancer

This resource is for people living with endometrial cancer (EC) and it's here to:

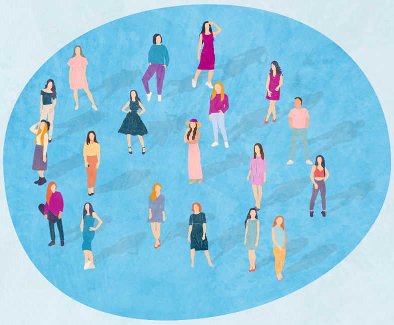
- Help you understand how it can impact your life
- Support you in speaking up and getting the help you need
- Connect you with support groups and useful resources

This resource is fully funded & initiated by Eisai Europe Ltd

A guide for people living with endometrial cancer

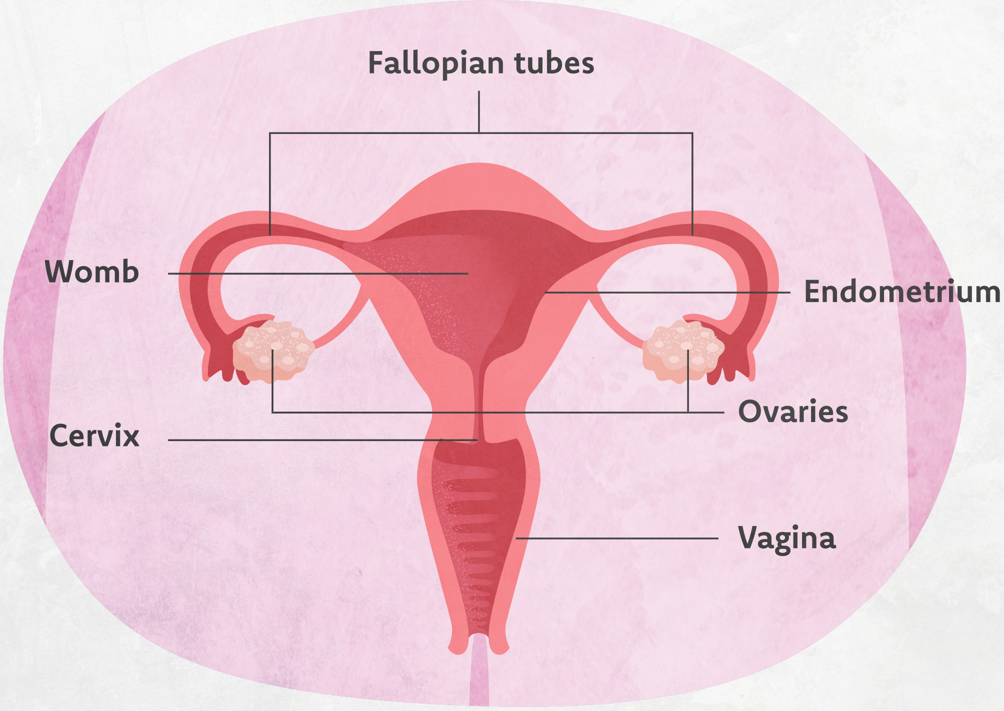
For many people living with endometrial cancer (EC), being diagnosed and adjusting to life with EC can be overwhelming and isolating.[1] It can be hard to speak up and ask for help or support from friends, family or healthcare professionals.

This guide has been created by a team of people living with EC and EC patient organisations to help the EC community navigate complex conversations and make informed decisions. You might find it helpful to bring this to your medical appointments.



Understanding EC

Cancer is a condition where cells in a certain part of the body grow uncontrollably.[2] EC is when cancer cells begin growing in the endometrium. This is the inner lining of the womb (or uterus). Anyone with a womb can have EC.[3] A hysterectomy is a surgery to remove the womb and is the main treatment for EC.[4]



Adapted from https://www.nhs.uk/conditions/womb-cancer/

How endometrial cancer can impact your life

Endometrial cancer (EC) can impact many aspects of your life including:

- **Physical health:** Common symptoms to be aware of:[5–7]
  - Unusual vaginal bleeding or spotting including bleeding after the menopause, between periods or bleeding that is heavier than usual
  - A change to your vaginal discharge, including pink, brown or red discharge
  - Unexplained pelvic pain
  - Weight loss
- **Personal identity:** Being diagnosed with EC and going through treatment can affect how you see yourself.[8] Changes to your body, fertility or relationships can change your sense of identity, leaving you feeling disconnected from who you were before.[9,10] It's okay to grieve those changes and speak up about them.
- **Emotional and mental wellbeing:** Receiving an EC diagnosis and living with EC can have a big impact on your emotional and mental wellbeing. It's important to give yourself time to process your feelings[11] and share your concerns with the people around you. Here are some common feelings people living with EC may experience:
  - Anxiety after diagnosis, during treatment, follow-up tests or appointments[12,13]
  - Worry about the future, or whether the cancer will come back[13]
  - Loneliness or isolation, especially if people around you don't fully understand what you're going through[1]
- **Relationships and social life:** EC diagnosis and treatment can bring emotional and physical changes that can affect relationships with partners, family, and friends. Open communication is key, as it's often hard to talk about these challenges. While some relationships may strain, others can grow stronger through support and understanding.[14]
- **Sex life and intimacy:** Changes in sexual health are common for people with EC, due to symptoms or treatment affecting sex in various ways, like pain and vaginal dryness.[15] Physical changes may cause you to have a feeling of loss of femininity and affect your self-esteem.[8] Be open with your healthcare team about the challenges that you're facing. If you're part of the LGBTQI+ community, then ask healthcare professionals to use your preferred pronouns and any language that you prefer.[16]
- **Concerns about Lynch Syndrome:** Lynch Syndrome is a condition that increases your risk of developing certain cancers including EC.[17,18] Because of this, if you're diagnosed with EC, especially if you're under 50, your doctor should test you for Lynch Syndrome.[17,19]

Speaking to your healthcare team

Doctors and nurses are medical professionals who are trained to help you, but you know yourself best. Speak to them about what is worrying you and what you need. You may find it helpful to keep a record of your symptoms and any questions you have and bring these to future medical appointments.

Questions to help you reflect

It's important to take time to reflect on how you're feeling and where you might need additional support. Here are some questions to think about:

What are your main concerns right now ?

Which symptoms affect you the most and how do they impact your life ?

How are you coping emotionally and mentally? What support might help ?

Have any activities, work tasks, or personal goals become more difficult recently ?

How have your relationships and social life been affected, and what support could help ?

Has your sex life been impacted ?

How has your diagnosis or treatment affected how you feel about yourself or your self-esteem ?

How have your future plans changed ? (Such as your career or family planning)

How are your loved ones coping? Do they know where to go for support ?

How comfortable are you asking for help ?

Do you know where to go for additional support ?

Example questions to ask your healthcare team

It's important to speak to your healthcare team about any concerns you may have. They are there to help you through your journey. Remember, all questions are valid. Below are some questions that you may want to ask as a starting point:

- What can I do to manage the symptoms that affect me the most ?
- What is the aim of my treatment, and what side effects can I expect ?
- How can side effects be managed, and who should I talk to about them ?
- Where can I get support for my emotional and mental wellbeing ?
- Who can help with advice on managing finances and employment ?
- How might endometrial cancer (EC) affect my relationships, sex life, fertility, or family planning – and who can support me with this ?
- Which healthcare professionals should I speak with for different issues relating to EC e.g. bleeding, physical pain, menopausal symptoms and impact and how do I reach them ?
- What support is available if I require help managing carer responsibilities (e.g. for children or parents) ?
- What support is available to help me manage things at home ?
- Have I been tested for Lynch Syndrome ?
- If I have Lynch Syndrome, what does this mean for my family ?

Additional resources

You may find these resources helpful to learn more.
Please note that the below links will redirect you to external websites that are not owned or controlled by Eisai.

ESGO ENGAGE's EC brochure ›

Peaches Trust support videos ›

Peaches Trust resources page ›

The Eve Appeal's dedicated EC page ›

The Eve Appeal's Lynch syndrome resource ›

Patient organisations

Patient organisations for people with endometrial cancer can provide additional support. They may be able to provide further information, helplines and allow you to connect with other people living with it. Connect with organisations in your local country to find out how they can help. Please note that the below links will redirect you to external websites that are not owned or controlled by Eisai.

ElleHelp	info@ellehelp.ch	🇨🇭
"Erifyle" Patient Initiative for Gynecological Cancers	erifylegyncancergr@gmail.com	🇬🇷
Gyncancerförbundet	info@gyncancerforbundet.se	🇸🇪
HaBait Shel Bar	bar@women-cancer.org	🇮🇱
Lady Garden Foundation	info@ladygardenfoundation.com	🇬🇧
Movimento Oncológico Ginecológico	info@mogportugal.pt	🇵🇹
ONKO Unie	jindriska.paleckova@onko-unie.cz; petra.adamkova@onko-unie.cz	🇨🇿
Peaches Womb Cancer Trust	admin@peachestrust.org	🇬🇧
Suomen Gynekologiset Syöpäpotilaat ry – Gynekologiska Cancerpatienterna i Finland rf	info@gysy.fi	🇫🇮
Veronica	info@pacientska-organizace.cz	🇨🇿
The Eve Appeal	office@eveappeal.org.uk	🇬🇧

This guide has been developed for the community by the community. We would like to thank Bar Levy (HaBait Shel Bar), Grace Teeling (Peaches Womb Cancer Trust), Helen Hyndman, MBE (The Eve Appeal) and Maria Papageorgiou (Erifyle) for their contribution to the development of this guide.

References can be accessed here.

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