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Oncology

Fast Facts for Patients

Sexual and Reproductive Health After Gynaecological Cancer

Karger

HEALTHCARE

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Sexual Health After Gynaecological Cancer

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With many thanks to Dana Braithwaite (Sexual Counsellor), Kate Walsh (Physiotherapist) and Fiona Houghton (Clinical Nurse Specialist) for their contributions.

We are grateful to all the women we have had the privilege to look after, and who inspired us with their stories to write this book. We dedicate this book to them.

Karger

HEALTHCARE

Why we wrote this book

This book was written for you, and for every woman affected by gynaecological cancer. We wrote it after talking to women like you who shared with us their experiences of cancer and cancer treatment. We have preserved the anonymity of the women who took part in our focus groups, but we have included many of their comments in this book. And while each person's experience is unique, you may find it helpful to read about their experiences. Some of what they say may already resonate with you.

A diagnosis of cancer can trigger many emotions, including fear, anger and grief. You may feel a loss of identity, femininity or positive body image. For some women, the speed and shock of their diagnosis gives them little time to consider all the options.

Many women are left feeling stunned by what has happened to them and to their bodies.

You may be feeling anxious or sad about the diagnosis of cancer and have many questions about how it will affect your future and your close relationships. You may be worried about the effect of the cancer treatment on your sexual health and on your fertility, or how an early menopause can affect you. You may also want to know what other types of help and support are available, in addition to your treatment, and where you can access them. This book aims to give you the information and the knowledge you need to answer those questions.

This book was also written to help you frame the questions that you need to ask your healthcare team, to empower you to make treatment decisions; the ones that are right for you.

When we talk about gynaecological cancers, we talk about the organs you were born with, but not about how you identify with those organs. If you are LGBTQ+, you may have additional specific questions for your healthcare team about the care and support you receive. You may also have specific questions if you take hormones as part of a gender-affirming process.

Mohamed Mehasseb and **Paula Briggs**
(on behalf of the contributors)

Introduction

Gynaecological cancers affect a woman's reproductive organs. The five main types are ovarian, uterine, cervical, vaginal and vulval cancer. Some are more common than others. Most gynaecological cancers can be cured if they are found early.

Treatment for gynaecological cancers includes surgery, chemotherapy, radiotherapy or a combination of treatments (e.g. surgery then radiotherapy).

When you have cancer, a team of specialists will meet to discuss the best possible treatment for you. This team is called a multidisciplinary team. The treatment you have depends on how advanced your cancer is, your general health, whether you have been through the menopause and whether you want to get pregnant in future.

Cancer and its treatment can have a profound effect on our lives, including our sexual health and reproductive wellbeing and function. In this book, you can read about the types of cancer treatment and their side effects, which may include the menopause and loss of fertility. Other effects of cancer treatment relate to your sense of sexual wellbeing and to intimacy and connection to your partner. We discuss these issues and present some of the things that you and your healthcare team can do to manage or reduce them.

Cancer is an individual experience, but you do not have to face it alone. You may not meet them all, but a team of healthcare professionals will be involved in your treatment journey.

Your healthcare team may include some of the following:

GYNAECOLOGICAL ONCOLOGIST
A doctor who specialises in surgery for women's cancers

CONTINENCE ADVISOR
A specialist nurse or physiotherapist who gives advice and support to people with continence problems

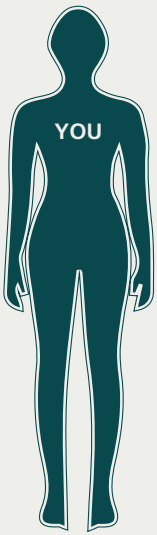
MEDICAL ONCOLOGIST
A doctor who specialises in chemotherapy and anticancer drugs

CLINICAL ONCOLOGIST
A doctor who specialises in radiotherapy

COLORECTAL SURGEON
A doctor who specialises in bowel surgery

MENOPAUSE SPECIALIST
To give advice on HRT and menopausal treatment

PALLIATIVE CARE DOCTOR OR NURSE
Who treats symptoms of advanced disease



CLINICAL NURSE SPECIALIST (CNS)

A clinical nurse specialist (CNS) is an advanced registered nurse who is specialised in a particular clinical area.

DIETITIAN
To help with your nutrition and dietary needs

PELVIC HEALTH PHYSIOTHERAPIST
A physiotherapist who specialises in the pelvic floor

SEXUAL AND RELATIONSHIP THERAPIST
A trained therapist offering advice, guidance and support to women and their partners after gynaecological cancer

GYNAECOLOGIST
A doctor who treats problems with the female reproductive system

GASTROENTEROLOGIST
A doctor who treats problems with the digestive system

FERTILITY SPECIALIST
To advise on your fertility options

PLASTIC SURGEON
A doctor who specialises in surgery to reconstruct external organs

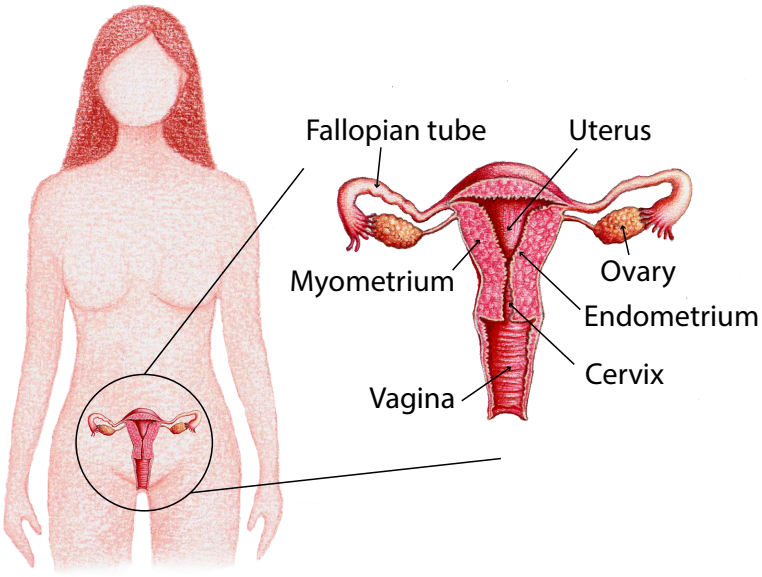
UROLOGIST
A doctor who specialises in kidney, ureter and bladder surgery

How your body works

When you know more about how your body works, it can be easier to talk with your healthcare team and to ask questions. This can also help you better understand your cancer, the treatment and the effects of that treatment.

Anatomy of female reproductive organs

Ovaries. The ovaries are small, walnut-sized organs located in the pelvis (lower part of the tummy). Normally, you cannot feel them. The ovaries produce eggs for fertilisation and the hormones **oestrogen** and **progesterone**.



Uterus. The uterus is also called the **womb**. It is usually the size of a pear and sits low in the pelvis, at the top of the vagina. It is formed of two parts: the upper thick part, called the **body**, and the lower thinner 'neck', called the **cervix**. The womb is held in place by many ligaments and muscles, called the **pelvic floor muscles**.

Myometrium. The middle layer of the uterine wall. It is mostly made up of muscle.

Fallopian tubes. The fallopian tubes link the ovaries to either side of the uterus. Fertilisation of an egg takes place in a fallopian tube. The fertilised egg then travels to the inside of the uterus where it develops into a baby.

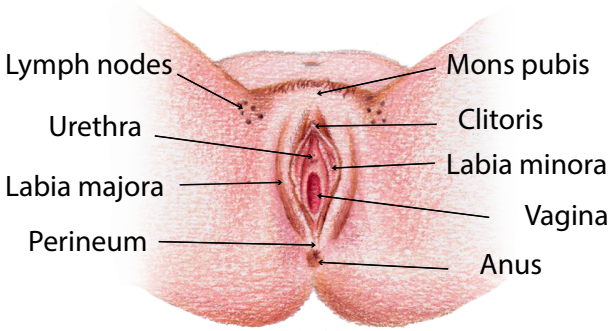
Peritoneum. The peritoneum is a thin sheet of tissue that wraps and supports the ovaries. The peritoneum also covers the internal organs in the tummy (abdomen), such as the liver and stomach, and lines the muscle walls of the abdomen.

Cervix. The cervix sits partly in the upper vagina and partly behind the bladder and in front of the rectum. Your cervix produces cervical mucus which helps sperm travel from the vagina into the uterus. The cervical mucus also protects the uterus from bacteria and infection. During childbirth the cervix opens to allow the baby to pass through.

Endometrium. The endometrium is the lining of the womb. It is the endometrium that responds to the hormones oestrogen and progesterone. The womb lining is usually shed every month if there is no fertilised egg. This is your monthly period (see page 10).

External reproductive organs

Vagina. The vagina is the passageway that runs from the cervix to the vulva.

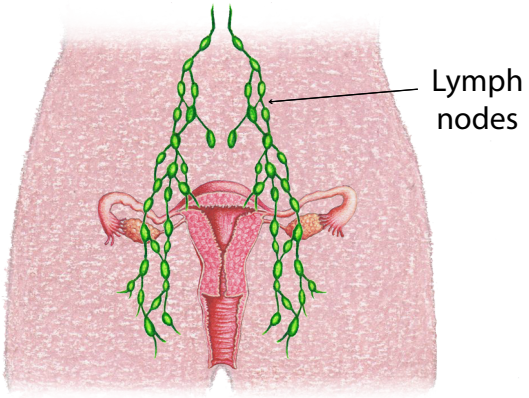


Vulva. The vulva is the part of the female reproductive system that is on the outside of the body. It includes the mons pubis, the labia majora (big lips) and minora (small lips), and the clitoris (important for sexual pleasure and orgasm).

Urethra the tube connected to the bladder through which urine passes when it is released from the body.

Perineum is the area between the vulva and the anus.

Your lymphatic system



Every organ in the body feeds into small glands called **lymph nodes** that are connected to each other by a network of thin tubes. Lymph nodes contain white blood cells that fight infection. The network of tubes is called the **lymphatic** (or lymph) **system**.

Why is the lymphatic system important?

The lymphatic system plays a very important role in our immune system. One of the functions of lymph nodes is to stop any infection or abnormal cells like cancer cells travelling through the body.

If cancer develops in your body, cancer cells can break off from the original tumour and travel through the lymphatic system to the lymph nodes. Lymph nodes act like a sieve or safety net by filtering the lymphatic fluid as it travels through your body. Lymph nodes often swell in response to infections or inflammation in the body.

Hormones and your periods

Your menstrual cycle is from the first day of your period to the first day of your next period. The average cycle in a woman who is menstruating regularly is around 21–35 days. The menstrual cycle is regulated by the hormones oestrogen and progesterone.

When you are born, your ovaries contain lots of eggs. The medical term for these eggs is **ova** or **follicles**. From puberty, an egg usually matures and is released from your ovaries each month. This process is controlled by two other hormones, called **follicle-stimulating hormone** (FSH) and **luteinising hormone** (LH).

FSH and LH also stimulate the ovaries to produce the hormones oestrogen and progesterone.

In the first phase of the menstrual cycle, the ovaries release oestrogen, which causes the lining of the womb to thicken. After ovulation, which is when the egg is released, rising levels of progesterone prepare the lining of the womb to receive a fertilised egg. If the egg is not fertilised, levels of progesterone and oestrogen fall, and the lining of the womb is shed – this is your period. When we talk about a woman's 'reproductive years' we mean those years when she is ovulating and most likely to become pregnant – on average – this is when you are between the ages of 14 and 45.

What is cancer?

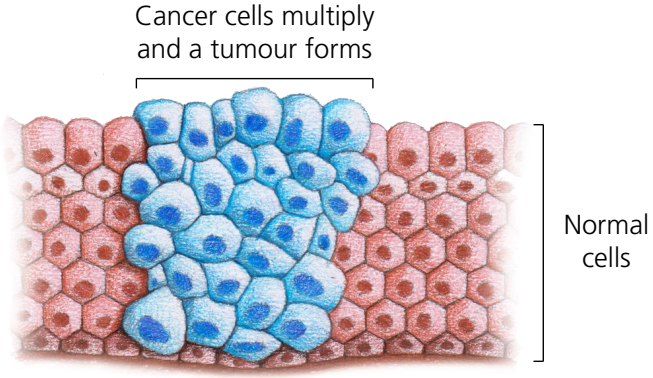
How cancer begins

Cancer begins when changes (**mutations**) occur in the genes of a cell or cells. Some mutations are inherited from a parent, are there from birth, and can be passed on to children. Other changes develop during a person's lifetime and cannot be passed on.

Most gynaecological cancer is not the result of inherited gene mutations. The mutations in the genes have happened in your lifetime.

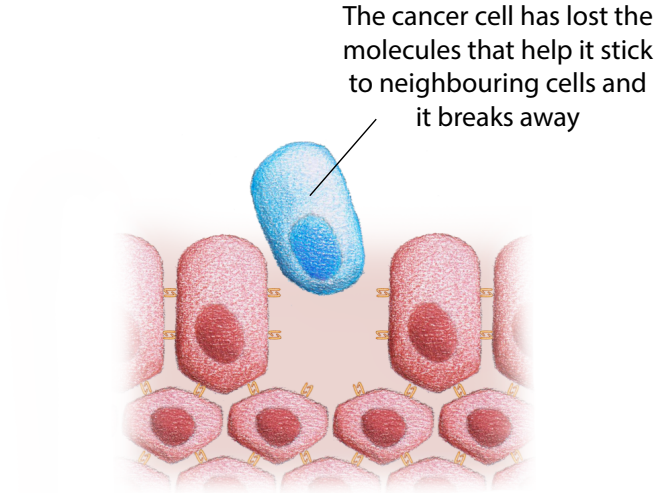
More about mutations

Mutations cause the affected genes to make abnormal proteins that can prevent the cell from working properly. Not all mutations result in cancer, but some give the cell properties that make it more likely to become cancerous if it collects a few more mutations.



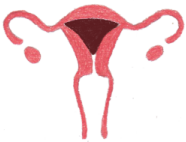
The most obvious cancer-causing mutations are those that cause the cell to keep multiplying. Normally, in adults, most cells only reproduce to replace worn-out cells and to repair damage. But cancer cells continue multiplying much more quickly than normal cells do. The excess cells form a lump or growth. This lump is a tumour.

There are other mutations that mean the cells lose their ability to stick together. This is why cancers can spread: the cancer cells can break away and travel through the blood and lymphatic system to another part of the body and start growing there. This process is called **metastasis**. When a cell has a mutation, it will pass it on every time the cell divides.

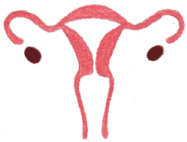


Gynaecological cancers

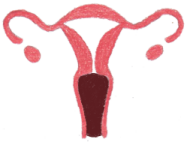
Each gynaecological cancer is different, with different signs and symptoms. Cancer can start in any of the reproductive organs and is named after the organ in which it begins.



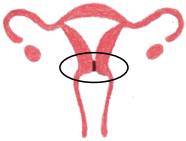
Endometrial/Uterine cancer



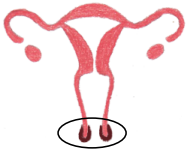
Ovarian cancer



Vaginal cancer



Cervical cancer



Vulval cancer

Different names are also given to the cancer depending on where in the organ it starts

- epithelial cancer starts in the lining of the organ
- squamous cell cancer starts in the skin
- adenocarcinoma starts in the glands
- leiomyosarcoma starts in the muscles
- sarcomas start in connective tissue.

What are the causes of gynaecological cancer?

We do not know what exactly causes the mutations in cells that lead to cancer. There are risk factors for all cancers and different gynaecological cancers have different risk factors. Having a risk factor does not mean that you will definitely develop cancer, though. It means that you are more likely than someone who does not have a risk factor to develop cancer.

My questions

How cancer can affect your sexual health and reproductive wellbeing

Sexual health and reproductive wellbeing are very important aspects of your physical and mental health. Gynaecological cancers and their treatment can have a significant effect on these aspects of your life.

What is sexual health?

Sexual health refers to your personal, psychological, relational and emotional wellbeing as it relates to your sexuality.

Talking with your healthcare team

It can sometimes be difficult to start a conversation about sex with someone from your healthcare team. Some women feel embarrassed or uncomfortable talking about something so personal. But it is important to ask questions and get the right information when you need it. When you understand why changes have happened, it may help relieve anxiety or worry, and it may help, too, when talking to your partner or other significant people.

> *"I had to wait to ask questions until I went for an outpatient appointment, and I had a very no-holds-barred discussion with my clinical nurse specialist. I really needed to know, what happens when you have a sex life?"*

Talking about what matters to you

You cannot assume that your healthcare team will ask you about your sexual health – you may well need to raise the topic yourself. Remember, though, that your healthcare team are there to help you.

The psychosocial and psychosexual effects of cancer

Cancer can cause changes in how you feel emotionally, how you see yourself, your self-confidence and how you think other people see you. The effects of these changes, which happen because of the cancer, its treatment and/or side effects of the treatment, are sometimes called **psychosocial effects**. It is also very common to have feelings that affect your sex life. These are sometimes called **psychosexual effects**.

Emotions

How you feel during this period is individual to you, but many women report experiencing similar emotions, from low mood and anxiety to frustration and anger. Sadness and shame are common, too. These feelings can relate to any aspect of the experience of having cancer and the effects of the treatment.

Some of the common emotions you might experience are discussed here.

Lack of confidence. The changes in your body may affect your body image and how you think others see you. You may feel less attractive and lack self-confidence.

Grief. Many women say that they grieve after treatment for cancer. This feeling is especially common after surgery or when treatment has affected fertility. Some women who have had surgery describe themselves as 'asymmetrical' or 'incomplete'.

"There was grief that I had lost those parts of me that were a woman. I felt like I was half of who I was before."

"I'd say I was in mourning for the fact that all my womanly bits had just been taken away and I had no choice. And although I never wanted to have children, that was my choice."

Fear is another emotion you may feel after treatment for cancer, particularly about re-establishing a sex life. In fact, pain during sexual intercourse (which is called **dyspareunia** in medical terms) remains the commonest problem after treatment for gynaecological cancer. Many women and their partners are nervous that penetrative sex will hurt or cause injury. This fear can make you avoid sex altogether.

Lack of interest in sex. A loss of interest in sex after treatment for cancer is very common and there are many reasons for it. Doctors refer to the loss of interest as **low libido** or **low sex drive**. It can happen because of fatigue or any of the reasons described above – a lack of confidence or a feeling that your partner is no longer attracted to you. You may lose interest because of discomfort or pain, or fear of pain; it can be a reaction to vaginal dryness or bleeding after sex, by sex not feeling the same, difficulty feeling aroused and reaching orgasm, or a reduction in sensitivity or a sense of numbness in your sexual organs.

What can you do about these feelings?

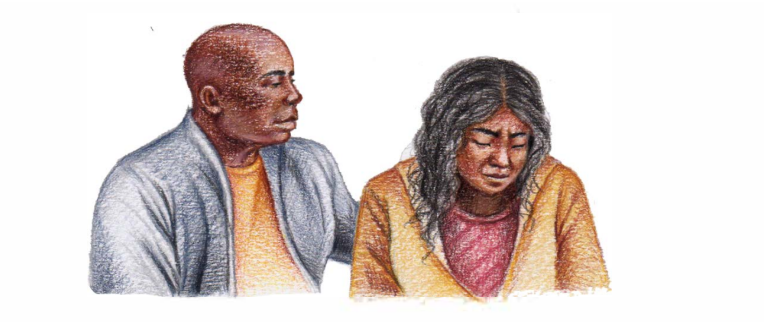
Give it time

Getting back to a satisfactory sex life can take a long time after cancer, and worrying about this aspect of your health and wellbeing is very common.

It is important not to put pressure on yourself at this time and to be patient. You do not have to rush into returning to your sex life and it may take months before you start to enjoy sex again. You may need to learn an entirely new way of being intimate with your partner. Initially, you may want to explore your body yourself to decide what feels comfortable and pleasurable for you and to communicate this to your partner.

The importance of communicating

For many women, sex after treatment for cancer just doesn't feel the way it used to. And while a satisfactory sexual relationship does not necessarily include vaginal penetration, many women are not convinced that this is something their partners will find acceptable. To avoid being rejected, a common response for many women is to distance themselves physically and emotionally from their partners.



We know that it can be difficult to talk about much of what you are going through, but not discussing sexual issues may deepen these fears. We would encourage you to be open and honest about your sexual relationship and talk to your partner. In most cases your partner will be equally anxious about resuming sexual relations out of fear of causing you pain.

Seeking support

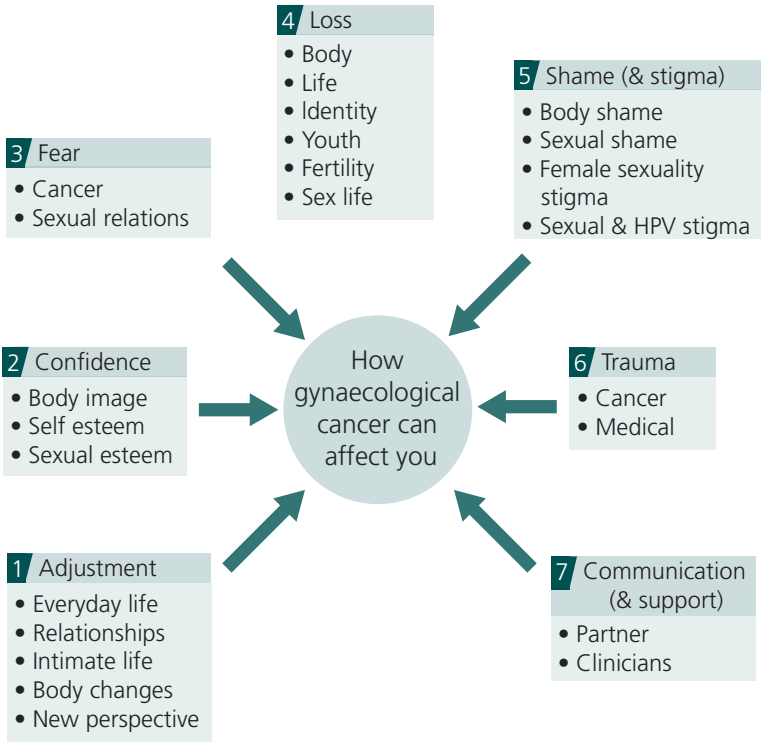
It is important to remember that you are not alone. Help and advice can often be found by talking to your key worker, if you have one (usually a clinical nurse specialist), or in a support group. Many of these groups are online. Talking about what you are feeling with other people who have experienced something similar to you can be easier than talking to family or friends.

Your partner and family

While cancer is an individual experience, and it has happened to you, your partner (if you have one), and close family will also be experiencing a range of emotions. They may have feelings of anxiety (burden), fatigue, distress and depression. Feelings of loneliness, hopelessness, insecurity, life crisis and neglecting their own needs are not unusual.

Counselling can be enormously helpful for couples to learn to communicate about their needs, their fears and worries after cancer. See pages 62–5 for more about this.

"Just like there's a checklist of symptoms, there's a checklist of emotions, too. But you're not going to have them all."



Cancer treatment and body changes

In the following pages you can read about the treatments for gynaecological cancers. You can also read about some of the changes a woman can experience because of her treatment and how these changes can affect sexual health and wellbeing. We also suggest things that you and your healthcare team can do to manage or reduce the impact of these changes.

Surgery

Surgery for gynaecological cancers may involve the removal of parts of your body that are important for reproductive and sexual function. Here, we present more details about surgery and the side effects that may follow. We talk about the effects of surgery on your emotional and psychological wellbeing on pages 15–20.

Hysterectomy

A hysterectomy is the partial or total removal of the womb. It may also involve removal of the fallopian tubes, cervix and ovaries. A hysterectomy can lead to a loss of sexual pleasure as some women feel the womb muscles contract strongly during orgasm. A hysterectomy can also result in a shortening of the vagina. You may find sex feels different or that it is harder to get aroused or to orgasm.

Removal of the ovaries

When a woman has her ovaries removed as part of surgery, she will undergo **surgical menopause**. This means that the menopause is caused by the surgery. Symptoms of the menopause can begin very quickly – sometimes in just a few days after surgery. The rapid onset of the menopause can be

very distressing for many women. The women we spoke to when writing this book all said they felt anxious about the menopause and unprepared for some of the changes that occurred. Symptoms of the menopause include hot flushes and night sweats, difficulty sleeping, brain fog, mood changes, joint and muscle pain, vaginal dryness and urinary symptoms.

> *"I knew I would have menopause soon after [treatment] which I was also terrified about. And it hit me like a ton of bricks. I literally woke up the next day and was in hot flushes and I couldn't take HRT until I'd finished my chemo and radiotherapy."*

> *"When I heard that I was going through the menopause, I thought, Oh my God, I'm going to go old, I'm going to grow old."*

There are other symptoms of menopause that can be challenging to live with. We talk more about these and things you can do to manage them on pages 37–45.

Some women who have been treated for certain types of gynaecological cancer can receive hormone replacement therapy (HRT) following radiotherapy and surgically induced menopause. HRT is widely used and can be safe, but whether it is appropriate for you depends on your individual circumstances. We talk more about this on pages 46–9.

Vulvectomy

A vulvectomy is the removal of part or all of your vulva and this may include the clitoris. Plastic reconstructive surgery may help restore the appearance, but function may not be totally returned to normal. Scar tissue can make penetrative sex painful. If the clitoris has been removed, orgasm may no longer be possible.

Vaginectomy

A vaginectomy is the removal of the whole vagina. A new or artificial vagina can then be created with vaginal reconstruction surgery, using skin and muscle from other parts of your body. This is not something that all women can have or that all women want. The reconstruction can result in a loss or change in sensation, and orgasm may be harder to achieve. It is important to be as informed as possible of the benefits and risks of this kind of surgery.

Pelvic exenteration

A pelvic exenteration is the removal of your bladder and/or bowel along with the gynaecological organs. This surgery is usually done when cervical cancer has come back after other treatments have not been successful at clearing the disease. A pelvic exenteration is a big operation and results in significant bodily changes.

Chemotherapy

As part of your treatment plan, you may be offered chemotherapy. Chemotherapy uses anti-cancer drugs to destroy cancer cells. It can be given as a drip (infusion) into a vein, or as tablets or capsules, depending on the type of cancer you have. Chemotherapy may be given as the main treatment for cancer, or to shrink a tumour before surgery or radiotherapy. This is called **neo-adjuvant chemotherapy**.

Chemotherapy can also be given to minimise the chance of cancer coming back after surgery or radiotherapy. This is called **adjuvant chemotherapy**.

Chemotherapy may also be given at the same time as radiotherapy, to make it work better. This is called **chemoradiation**.

When the cancer has spread into surrounding areas (called **locally advanced cancer**) or to other parts of the body (called **advanced** or **metastatic** cancer), **palliative chemotherapy** can be used to shrink and control the cancer to try to prolong life, and to relieve symptoms.

Side effects of chemotherapy

Chemotherapy targets cancer cells, but it also affects the healthy cells in your body, and this causes side effects. There are many different side effects of chemotherapy. Many cancer associations and patient organisations have detailed information on the side effects and how to manage them. We list some trusted websites and resources at the back of this book.

How long do side effects last?

Many side effects are temporary. They may get worse for a couple of weeks after treatment, then usually improve

slowly over a few weeks. Some side effects last for a long time, however, or appear many months after treatment has finished. In some cases, side effects can be permanent.

Tell your healthcare team how you feel

It is important that you tell your healthcare team of any changes in the way your body feels. Keeping a diary or a checklist of how you feel can be helpful.

How does chemotherapy affect sexual health and wellbeing?

The following are some of the most common side effects of chemotherapy that may impact your sexual health and wellbeing.

Fatigue is extreme tiredness that makes you struggle with your day-to-day activities, including sex. Nearly everybody being treated for cancer will experience this. You can find advice on how to manage cancer-related fatigue on page 33.

Body image. Your confidence and body image may be affected by the chemotherapy, as it can cause a temporary loss of head and body hair, eyelashes and pubic hair. Some additional medications you may require, such as steroids, can result in weight gain. You may not feel as attractive and may avoid socialising and intimacy as a result.

Infections. Chemotherapy affects your body's immune system, and you are more likely to catch infections. You may feel anxious about this, particularly if you do not have a regular partner, and you may want to avoid intimacy as a result. Vaginal thrush is also a common side effect of treatment.

Nausea. Chemotherapy can make you feel nauseous; you may also be physically sick. In addition, you may experience stomach aches and diarrhoea. Sex and intimacy are likely to be the last things on your mind.

Radiotherapy

Radiotherapy is the use of high-energy radiation to treat cancer. You may have pelvic radiotherapy as part of your treatment for cervical cancer, womb (endometrial) cancer, vaginal cancer or vulval cancer. It is not generally used for ovarian cancer.

Radiotherapy to the pelvis can be given internally; small doses of radiation are delivered to the top of the vagina and centre of the pelvis. This is called **internal radiotherapy** or **brachytherapy**.

Radiotherapy can also be given from outside the body to cover a wider area of the pelvis. This is called **external beam radiotherapy** or teletherapy. You may have both external and internal radiotherapy treatment.

As previously mentioned, you may also receive chemotherapy with radiotherapy. This is called **chemoradiation**.

Side effects of radiotherapy

Most people having radiotherapy will have some side effects during or after treatment. The specific side effects that you have will depend on

- the type of radiotherapy you receive
- the area of your body being treated
- other treatments you are also having, such as chemotherapy.

How long do side effects last?

Many side effects are temporary. They may get worse for a couple of weeks after treatment then usually improve slowly over a few weeks. Some side effects last for a long time, however, or appear many months after treatment has finished. In some cases, side effects can be permanent.

How does radiotherapy affect sexual health and wellbeing?

The following are some of the most common side effects of pelvic radiotherapy that can affect your sexual health and wellbeing.

Fatigue is extreme tiredness that makes you struggle with your day-to-day activities. This will impact on your sex life as well. Fatigue can persist for many months after treatment. Most people treated for cancer will experience cancer-related fatigue. You can read some suggestions on how to manage cancer-related fatigue on page 33.

Skin. The skin in the area being treated can get dry and irritated. This can be uncomfortable, particularly around the anus, the vulva, either side of the groin and between

the buttocks. Your skin may become red or get darker. It may also feel warm, itchy or sore. Sometimes the skin may blister, break or leak fluid. Your healthcare team can prescribe products specifically for these side effects.

Changes to your bladder. Pelvic radiotherapy can irritate the lining of your bladder. You may have a burning sensation when you pass urine (**dysuria**) or see small amounts of blood in your urine. You may feel the need to pass urine more frequently or you may leak small amounts of urine (**incontinence**) or have the sensation that you need to pass urine urgently. Pelvic floor physiotherapy can be very helpful for many of these issues. This is discussed in more detail on pages 50–3.

Changes to your vagina. Pelvic radiotherapy can cause vaginal dryness, scarring, shortening and narrowing. This is called **vaginal stenosis** and can make internal examinations and sex painful. You may bleed after sex, as the blood vessels in the lining of the vagina may become fragile.

You may be prescribed lubricants to use before and during attempted vaginal sex and vaginal moisturisers can help with dryness. Vaginal oestrogen (applied as creams, gels or pessaries) is another potential treatment option for dryness depending on your individual circumstances.

Your healthcare team might ask you to use **vaginal dilators** with lubricants to help stop the vagina from narrowing or shortening. This is sometimes called dilator therapy.

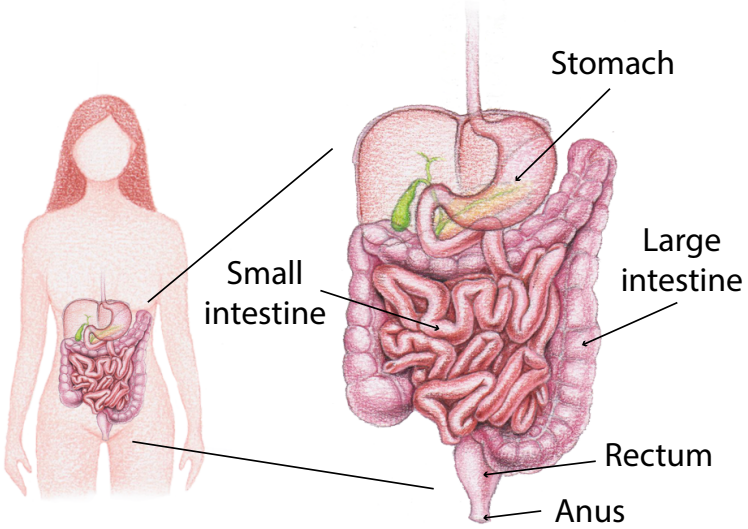
A **dilator** is a tube-shaped device that you use regularly to gently stretch the vagina to prevent it from narrowing. How long and how often you use dilator therapy for depends on you – somewhere between 6 and 9 months is common.

The dilators come in a kit with different sizes. They're made from different materials such as plastic, acrylic or silicone and are used with a water-based lubricant. Your healthcare provider may provide the kit or you may need to buy your own from a pharmacy or online.

Dilator therapy is not easy for all women to do as some women feel uncomfortable with the concept. It can be painful at first, but regular practice can result in considerable improvements. An alternative option is to use a tapered vibrator. If you have questions or need advice about dilator therapy, a nurse, psychosexual therapist or pelvic health physiotherapist will likely be able to help. You can also find helpful videos on some of the resource websites we list at the back of this book.

Changes to your bowel. You may experience some diarrhoea after pelvic radiotherapy or the opposite – constipation. You may feel gassy and/or have cramping pains in your abdomen or your rectum.

Some other, less common, side effects are: feeling you need to go to the toilet even though your bowel is empty, mucus or blood when you poo, bleeding from piles (**haemorrhoids**) and/or some leakage (**incontinence**).



Radiotherapy can also cause scarring (fibrosis) in the **large intestine**. This can make the large intestine narrower, thicker and less flexible. The large intestine is also called the **large bowel**. Sometimes radiotherapy can cause changes in the **small intestine**, too, making it difficult to digest some types of food (food intolerance). The small intestine is also called the **small bowel**.

Changes to the anus or rectum may affect your sex life if you are the receptive partner for anal sex. Anal and rectal changes can also affect how it feels to receive vaginal sex as the rectum and vagina are very close together. Your healthcare team may advise you to wait for a time after receiving radiotherapy before you try having sex. Your body needs time to heal. Sometimes anal sex will no longer be possible or safe.

Lymphoedema. Pelvic radiotherapy may increase the risk of swelling and fluid collection in one or both legs. This is called lymphoedema. It is caused by damage to your lymphatic system. What treatment you have depends on the severity – always tell your healthcare team immediately if you notice any swelling in your body.

Gentle exercise and compression stockings are helpful in mild cases, and you may also benefit from massages or a treatment called **lymphatic drainage**. In more serious cases your healthcare team may refer you to the lymphoedema service for specialist input. Rarely, and in extreme cases, you may benefit from plastic surgery to cut away excessive tissue in the legs.

Radiotherapy and your ovaries

Early menopause

The ovaries are particularly sensitive to radiotherapy and are likely to stop working when exposed to radiation. If you are still having periods, radiotherapy will most likely cause a premature or early menopause. You can read about menopause on pages 35–45.

Fertility

Pelvic radiotherapy has a damaging effect on the lining of the womb and on the eggs in the ovaries. This often means you will not be able to get pregnant or carry a pregnancy after treatment.

Preserving fertility. There may be options for preserving your fertility and we talk more about this on pages 56–61. You may meet with a fertility specialist to discuss the possibility of storing embryos, or eggs or ovarian tissue. It may be possible to use these to start a pregnancy that someone else carries (a **surrogate**). You may have surgery to move the ovaries away from the area having treatment. This is called **ovarian transposition**.

However, it is not always possible to preserve fertility in a woman with gynaecological cancer. Your risk of infertility depends both on the dose of radiotherapy you have and your age. Fertility is less affected by chemotherapy.

Managing cancer-related fatigue

There are things you can do to help reduce the impact of fatigue on your life, irrespective of the cause.

Prioritise activities

Not everything is a priority. Learning which tasks to focus on and which tasks to leave for another day – or delegate to someone else – can be an important strategy to manage fatigue. Many people have more energy at certain parts of the day. Listening to your body and not attempting tiring tasks when your energy levels are low can also be very helpful.

Conserve energy

Feeling energetic on certain days can sometimes drive people to do more than their body can manage, and more fatigue results. Even simple tasks can be tiring so finding ways to conserve your energy can be very helpful.

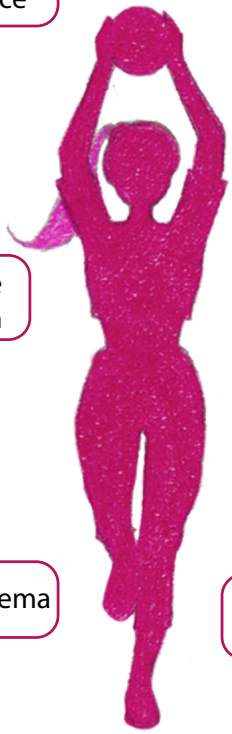
Put yourself first

Saying 'no' to family members who want you to socialise when you are not up to it, or not helping with childcare as frequently as you used to, can be hard to do. Explaining not only how you physically feel, but why you feel like this may help others to better understand.

Managing treatment side effects with exercise

Exercise is one of the very best things you can do to manage cancer-related fatigue and there are scientific studies that prove just how beneficial it is. Exercise is also a great way to manage many of the other side effects of cancer treatment that we have referred to in the previous pages.

Exercise improves…



- balance
- quality of sleep
- aerobic capacity
- quality of life
- immune function
- tolerance to treatment
- pelvic floor function
- muscle condition
- lymphoedema
- bone density
- mood and sense of control

... and reduces cancer-related fatigue.

Menopause and gynaecological cancers

What is the menopause?

Menopause is a retrospective diagnosis 12 months after a women has her last menstrual period. However, the word menopause is also used to describe the time around this event when many women experience symptoms. The menopause is associated with a significant reduction in oestrogen production from the ovaries and this is much more extreme in surgical menopause, when the ovaries are removed. You may have already reached natural menopause before being diagnosed with cancer, and so you may have already been through the period called **perimenopause**, when ovarian function starts to decline. This can last a number of years, during which your periods are likely to become irregular and eventually stop.

Surgical menopause

If you received extended radiotherapy to the pelvis, your ovaries will likely have stopped working. This can lead to a sudden beginning of menopausal symptoms. The speed with which you enter menopause is similar to that of surgical menopause and so can be more difficult to cope with for many women.

In the following pages you will read about the most common symptoms of menopause, their effect on your daily life and sexual health and wellbeing and the things that you and your healthcare team can do to reduce them to make life more comfortable.

How will the menopause affect me?

The menopause affects different women in different ways. There are many possible symptoms – and you may not have any of them or you may experience some or all of them – some or all of the time.

My menopausal symptoms

Use this table to keep track of your symptoms over 2–3 weeks. Make a note of the severity of your symptoms – mild: 1, moderate: 2, severe: 3 – and how long the symptoms last.

Week beginning:			
Hot flushes			
Night sweats			
Vaginal dryness			
Emotional instability*			
Bladder problems**			
Poor sleep			
Forgetfulness			
Poor concentration			
Difficulty coping			
Lack of drive			
Anxiety			
Depression			
Changes to the hair			
Changes to the skin			
Loss of interest in sex (low libido)			
Joint pains			
Muscle pains			
Headaches			
Palpitations (racing heart)			
Other...			

*For example, irritation, tearfulness.

**Urgent need to pass urine, incontinence, overactive bladder.

Managing your symptoms

Your healthcare team should discuss ways to manage these symptoms before you have treatment and put in place an individualised plan, guided by your medical history.

Hot flushes

Hot flushes are a sudden feeling of intense heat that spreads throughout the body. They may last a few seconds or many minutes. Your skin may turn red, you may sweat and sometimes you may have palpitations (rapid heart rate).

Hot flushes are one of the most common and well-known symptoms of the menopause. They can also be very uncomfortable and can be quite alarming when you first experience them.

Hot flushes can lead to embarrassment and anxiety for many women. Hot flushes can continue for many years for some women, and the frequency also varies. Some women have very few, whereas others may get many hot flushes each day.

> *"The one symptom that everyone knows about menopause is the hot flushes, but I think a description of what they actually are would help, because for me, before I had them, I thought it was just something that came and went instantly. But it was like somebody throwing buckets of boiling hot water over me. And they last, they're not fleeting, they do not come and go. They actually last."*

In women being treated for cancer, menopausal symptoms may be more severe. The team looking after you will do their best to find the safest way of managing these symptoms.

What you can do

- Wear several thin layers of clothing and choose clothes that you can remove quickly and easily.
- Carry a fan with you or try neck-cooling scarves/ bandanas.
- Cool your face with cold water if you feel a hot flush coming on.
- Avoid triggers such as spicy food, alcohol and caffeine.
- Check whether any medicine you are taking increases the risk of hot flushes; talk to your doctor if you think this is an issue.
- Use relaxation and breathing techniques to avoid stress and anxiety, as they can make hot flushes worse.
- Femal is a food supplement made from grass pollen and has been shown to reduce hot flushes. You can find more information about this hormone-free product on the website listed in the 'Useful resources' section at the back of this book, but it is important to check with your specialist before using any treatment, even things which do not require a prescription.

How your doctor can help

- HRT is the recommended treatment for hot flushes and can be highly effective (see pages 46–9). However, it may not be suitable for women with some types of cancer.
- Your doctor may prescribe medications called SSRIs or SNRIs (selective serotonin- or norepinephrine-reuptake inhibitors). These medications are generally used to treat depression, but they are also effective at reducing hot flushes and may be helpful if HRT is not an option.
- Other drugs – including oxybutinin, gabapentin and clonidine – may also help to reduce hot flushes. All these medications are licensed to be prescribed for other conditions.

Night sweats

Night sweats are hot flushes that happen during the night. You may wake up feeling 'wet with sweat'. They can disturb your sleep (and your partner's), and disturbed sleep can cause tiredness. Being tired every day is hard to cope with for many women, particularly if it is not possible to catch up on your sleep during the day.

> *"I found the night sweats hard…waking you up and then not being able to get back to sleep again. So there was just a continual tiredness because of that vicious circle."*

What you can do

- Wear fewer and/or looser clothes at night.
- Have two single duvets on your bed, so that you and your partner can each choose the level of warmth that works for you.
- Try a cooling pillow.
- Avoid triggers, such as spicy food, alcohol and caffeine, particularly in the evening.
- Check whether any of your medications are associated with night sweats; talk to your doctor if you think this is an issue.

How your doctor can help

- HRT is highly effective in controlling night sweats and improving sleep patterns, if it is an option for you (see pages 46–9).
- If HRT is not an option, there are alternative medications that can be prescribed and a new class of drug called a 'neurokinin antagonist' which will be available soon.

Vaginal dryness

Vaginal dryness is a very common symptom of the menopause, but women are often embarrassed to talk about it. The medical term is **urogenital atrophy** or genitourinary syndrome of menopause. Surgery may also lead to a shorter or scarred vagina, and radiotherapy can cause further damage to the vulval skin. Urogenital atrophy may cause discomfort or pain during sex. It can also make a smear test difficult or painful (if still required).

In general, urogenital atrophy is best managed with treatments that are delivered directly to the vulva and vagina.

What you can do

- Use lubricants during sex. These are widely available in pharmacies or online.
- Try vaginal moisturisers, available from pharmacies or online (e.g. Sylk, YES VM).

How your doctor can help

- Your doctor can prescribe vaginal moisturisers, which you generally use twice a week to reduce vaginal dryness.
- You may be eligible for treatment with low-dose oestrogen delivered directly to the vagina. This is available as a pessary, cream, gel or vaginal ring.
- Another treatment option is a product called 'prasterone', which is a pessary inserted into the vagina daily. It releases a precursor hormone called dehydroepiandrosterone or DHEA. A precursor hormone has little effect on its own but converts into another hormone in the body. DHEA is converted in the lining of the vagina to oestrogen and testosterone. There is virtually no absorption into the bloodstream.

- If these treatments do not work, your doctor may prescribe a drug called 'ospemifene'. It is taken by mouth and improves tissue quality. It is generally used alone, is not added to HRT and cannot be used in some clinical situations. Your doctor will know if it's appropriate for you.

If you are due for a smear test, using one of these treatments for 3–6 months beforehand will help make the procedure easier and less painful for you. It is important that you continue to have regular smear tests if advised to do so.

Bladder problems

You may experience a sudden or constant need to pass urine or you may start to pass urine before you reach the bathroom. The medical term for this is **urge/urgency incontinence.** You may leak some urine during exercise or when laughing or coughing. The medical term for this is **stress incontinence**. Or you may experience both, which is called **mixed incontinence**. You may also find that it is painful to pass urine.

Having an overactive bladder can increase the need to pass urine, including during the night, which disrupts sleep.

What causes bladder problems in menopause?

Lack of oestrogen. A lack of oestrogen causes the tissues in your vulva, vagina, bladder and urethra (the tube that carries urine out of the body) to lose their elasticity. Radiotherapy may make these symptoms more pronounced.

Pelvic floor weakness. Your pelvic floor can be weakened by several things, including gynaecological cancer treatment, childbirth and simply getting older. When you are standing, most of your body weight bears down on the pelvic floor, and being overweight can make this worse.

A past history of pregnancy and childbirth may indicate that there has been significant pressure on the pelvic floor, especially if a baby was large, labour was long, or instruments were used to help the delivery. Coughing and constipation can also increase stress on the pelvic floor.

What you can do

- Pelvic floor exercises (also called Kegel exercises) strengthen the pelvic floor and can therefore help with bladder control.
- A few sessions with a specialist pelvic floor physiotherapist can be very helpful. You can continue to do the exercises demonstrated when you are at home. For more information about this, see pages 50–3.
- Yoga and Pilates are other forms of exercise that can strengthen the pelvic floor.
- Have your last drink at least 1 hour before going to bed.
- Try to reduce your intake of fizzy drinks, caffeine and alcohol, as these can worsen symptoms.
- Try to avoid spicy foods and artificial sweeteners as these may also irritate the bladder.

How your doctor can help

- If you are eligible, your doctor may be able to refer you to a specialist pelvic floor physiotherapist. For more information about what these specialists do, see pages 50–3.
- Your doctor can prescribe various treatments to improve urogenital tissue quality in addition to medication for an overactive bladder, if necessary.

How menopause affects your mood and mind

You are likely to experience changing emotions during your cancer journey but the changes in hormones during menopause can make this worse.

You may feel irritable or tearful, feel low or have anxiety and find it difficult to cope. Lack of sleep – because of anxiety or night sweats – can make all these symptoms worse. Some women also report becoming more forgetful, and they describe poor concentration and 'brain fog'. These symptoms can be alarming, but they are very common in menopause and usually settle in time.

> *"The brain fog. I didn't actually realise how serious that was going to be but I couldn't find words when I was talking to people… I was stumbling over what was the word for simple things like 'pen'."*

What you can do

- Your diet is important; try to eat well and reduce/avoid alcohol and caffeine.
- Try to exercise regularly; it is a particularly good way to improve your mood, as is being outdoors.
- Try relaxation techniques, breathing exercises and/or mindfulness. These can all help.
- Take time to look after yourself, away from the stresses of life and the demands of others.
- Tell your partner and family why you are feeling irritable. They are likely to be more supportive if they understand what you are going through.
- Consider getting support by talking to your friends and other women who understand what you are going through.
- If mood changes are affecting your quality of life, contact your doctor for help. There are a variety of treatments, including antidepressants (SSRIs and SNRIs) and other non-hormonal treatment options if HRT is not possible in your case, that you can discuss.

Sex and the menopause

In addition to the effects of cancer treatment, for some women, the hormonal changes during the menopause can affect libido (interest in sex) and cause problems such as vaginal dryness and soreness (urogenital atrophy), which can make sex difficult or painful. This may in turn affect sexual desire and arousal, with a significant effect on orgasm and sexual pleasure.

The changes associated with urogenital atrophy may affect sexual intimacy and the ability to have a physical loving relationship. Women also report feeling less healthy and attractive. This can lead to avoidance of sex and intimacy which is an important part of a relationship for many people. We talk more about these issues on pages 16–20.

Urogenital atrophy is also a common cause of bleeding after sex (postcoital bleeding). However, you may have been advised that bleeding may be a sign of the cancer coming back – so always check with your doctor.

What you can do

- Use lubricants to help during sex, and vaginal moisturisers to ease discomfort.
- Explore other types of stimulation and intimacy with your partner. Sex does not have to include penetration to be enjoyable.
- Find alternative ways to show affection and share intimacy with your partner. Even if you do not feel like having sex, affection is important and can help you feel better.

How your doctor can help

- Your doctor may be able to refer you to a specialist pelvic floor physiotherapist (see pages 50–3).
- Your doctor may be able to prescribe treatment to help with urogenital atrophy.

Where can I get more information and advice about the menopause?

There's lots of advice about the menopause online, but it can be hard to know where to go for reliable information. We list several trusted websites at the back of this book in the 'Useful resources' section. It is important to read trusted information about the menopause; however, always check with your healthcare team if you are unsure about anything you've read.

Hormone replacement therapy

If you have had a surgical treatment for a low-grade cancer in its early stages, you may be eligible for treatment with hormone replacement therapy (HRT).

What is HRT?

HRT replaces the oestrogen that you lose during the menopause. HRT can be either oestrogen on its own or in combination with a progestogen. A progestogen can be a synthetic version of the hormone progesterone, or a version called 'micronised progesterone' which is chemically identical to the hormone produced by the ovaries.

How can HRT help?

HRT can help to reduce menopausal symptoms. It can also reduce the long-term consequences of the menopause. Long-term consequences of menopause include the impact of a lack of oestrogen on urogenital tissue quality, a reduction in bone mineral density, which can increase the risk of osteoporosis and fractures, and an increase in the risk of cardiovascular events such as heart attacks, depending on individual risk factors.

How do I take HRT?

There are many products and delivery route options for HRT, including tablets, patches, gels, sprays and implants. This allows your HRT to be tailored to your needs. A patch, gel, spray or implant may be more suitable than tablets for some women, particularly those at higher risk of blood clots in the leg or the lung. You may need to try more than one type of HRT to find the one that suits you.

Is HRT safe?

In general, HRT is safe, particularly below the age of 60 when women are less likely to suffer from common health problems such as high blood pressure and type 2 diabetes. In relation to the impact of the cancer that you have had, it is important that the healthcare professional who is responsible for prescribing HRT takes the advice of the cancer team that have been responsible for your care.

Many women still worry about the risk of breast cancer in association with the use of HRT. The reality is that breast cancer is common, affecting up to one in seven women irrespective of HRT use. Hormone therapy can promote growth of a pre-existing, undiagnosed breast cancer, which means that affected women present sooner, and their outcome is the same.

For most women, fear of developing breast cancer should not prevent use of HRT, but for women with gynaecological cancer, these particular risks need to be considered very carefully.

Cancer and HRT

In general, most women with cervical, vaginal or vulval cancer can have HRT. Women with some types of uterine cancer and some types of ovarian cancer are also suitable for HRT.

HRT is not suitable for everyone, however. Do not start any hormone therapy before discussing the risks and benefits with the healthcare team treating your cancer.

Who cannot have HRT?

You may have a medical condition that makes HRT use high risk for you. Or the type of cancer you have may mean that HRT is best avoided to reduce the chance of

the cancer coming back. If HRT is not suitable for you, there are other non-hormonal treatment options to help with your menopausal symptoms. These include cognitive behavioural therapy, diet and exercise, and non-hormonal medication. Clonidine is a drug that is used to manage high blood pressure, but it can also be used for hot flushes and night sweats. Other non-hormonal treatments which can be prescribed include antidepressants like venlafaxine and mirtazapine. Your doctor does not think you are depressed but is suggesting these treatments for the other benefits that they might have on common menopausal symptoms. There are other options such as oxybutynin, pro-banthine and gabapentin.

Alternative therapies for the symptoms of menopause

There are various alternative or non-pharmaceutical therapies which many women say help with the symptoms of menopause. These include maca, ashwagandha, soy products, red clover and black cohosh. Because these types of products are not often tested (and are very rarely tested in the same way that pharmaceutical products are tested), it isn't clear how much they can help. Some women experience benefits, other women do not.

It is important to think about both the risks and the benefits, as you would for any medicine prescribed by a doctor. If you are considering using a non-pharmaceutical or alternative therapy, speak to your healthcare practitioner.

Questions to ask your doctor about HRT

With my kind of cancer, can I have HRT?

What kind of HRT do you recommend?

Why do you recommend this kind?

Are there other options?

How will it help?

How do I take it?

How long will I take HRT?

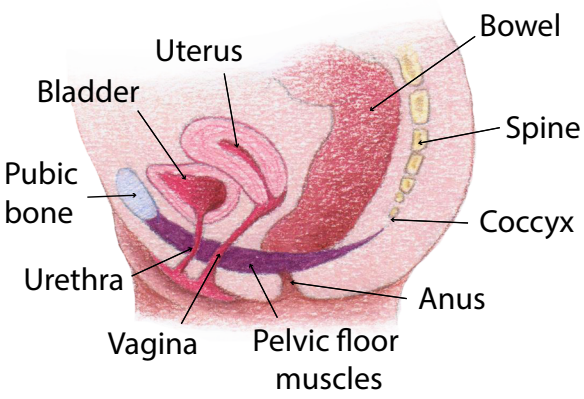
Are there any risks associated with this kind of HRT?

Are there any side effects associated with this kind of HRT?

Pelvic health after gynaecological cancer

What is pelvic health?

Pelvic health means the best possible functioning and management of the bladder, bowel and reproductive organs.



Why is the pelvic floor important?

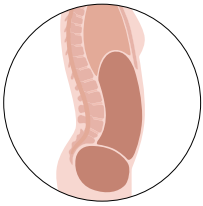
Your pelvic floor includes not only muscles, but fascia, ligaments, nerves and other connective tissue in the pelvic region. Your pelvic floor is key to supporting the pelvic organs and to promoting optimal bladder, bowel and sexual health.

How can the pelvic floor be weakened?

There are many causes of a weakened pelvic floor. They include the hormonal changes that happen at menopause, childbirth, heavy lifting, constipation and the resulting straining, by being overweight and ageing. Poor posture can also contribute.

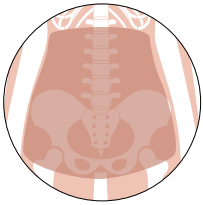
What is the function of the pelvic floor?

The pelvic floor has several important roles in the body.



Organ support. The pelvic floor helps to support your bladder, womb, rectum and other abdominal organs against the force of gravity and any other downward pressure (such as in pregnancy). **Pelvic organ prolapse** occurs when the pelvic organs bulge into the vagina because of weak pelvic floor muscles.

Sexual health. Pelvic floor muscles have an important role in how enjoyable sex is; muscles that don't relax can cause pain during sex. On the other hand, weakened muscles can be a factor in loss of sensation during orgasm.



Core support. Pelvic floor muscles help to keep your lower back and pelvis stable. Weak muscles can lead to lower back pain.

Bladder and bowel control. Weakened pelvic floor muscles can cause leakage of urine, poo (faeces) and gas.

What is pelvic physiotherapy?

Pelvic physiotherapy is specialist physiotherapy for any problem that relates to the pelvis. Problems that a pelvic physiotherapist can help with include bladder issues such as urge incontinence, bowel issues such as incontinence or constipation and other problems caused by weak pelvic floor muscles. Pelvic physio can help with painful sexual intercourse and pain in the pelvic joints.

What happens in pelvic physiotherapy?

A pelvic physiotherapist will

- assess the condition of your pelvic floor muscles by seeing how well you can contract and relax them
- assess the support of your pelvic organs, to make sure everything is as it should be
- evaluate your breathing and your posture and explain how to optimise them, if necessary
- work with you to develop a programme of exercises for your pelvic region. These exercises can help existing problems and also reduce the likelihood of any future problems happening.

Squeezy is an app that supports women and men with their pelvic floor muscle exercise programmes. It was designed by pelvic floor physiotherapists, costs just a few pounds and can help you learn how to do the exercises correctly and regularly.

You can read more about it and download it here **squeezyapp.com/**

Who can see a pelvic physiotherapist?

Specialist pelvic physiotherapy services can be found privately and within the NHS. They can be accessed via your GP or self-referral.

Anybody who is experiencing symptoms of pelvic floor dysfunction can seek the advice of a pelvic physiotherapist.

Complementary therapies

Complementary therapies are often used by people with cancer alongside conventional treatment to help reduce stress, fatigue and the impact of any treatment. You may hear complementary therapies referred to as 'alternative' therapies, or 'holistic' therapies.

Practices and therapies useful for people with cancer

Practices that people undergoing treatment for cancer use to manage their symptoms include yoga, tai chi, pilates and meditation while therapies include massage, reflexology, acupuncture and aromatherapy.

Yoga. There are different aspects to yoga – physical, breathing and meditation to name three – and many different styles of yoga. All can help energise the body and offer relief from fatigue, pain, stress and anxiety. Yoga can be done in a class or at home – there are many online yoga teachers offering free or low-cost classes.

Tai chi is a traditional Chinese martial art that combines slow movements with deep breathing and mental focus. It is an energising practice that can be done in a class or at home. Studies show that, like yoga, tai chi can help with pain relief, fatigue, sleep problems and depression.

Pilates is a form of low-impact exercise, similar to yoga, that focuses on balance, posture, strength and flexibility. Like yoga, it can be very helpful for strengthening core and pelvic floor muscles.

Massage and reflexology. Massage increases blood flow around the body and can ease pain and discomfort and help you feel relaxed. A massage therapist is usually also trained in **lymphatic drainage**, which is a hugely helpful therapy for people with lymphoedema of the leg or arm.

Reflexology works on pressure points in your feet or sometimes your hands. It can also promote a deep feeling of relaxation.

While massage and reflexology are both generally safe for people living with the side effects of cancer treatment, it is a good idea to find a practitioner who works with people with cancer and understands their specific needs. Lymphatic drainage, for example, will need to be done with a lighter touch.

Acupuncture uses needles to stimulate pressure points around the body. Electroacupuncture, where a small electric current is passed between two needles, is also used. Studies have shown that both types of acupuncture can give relief from pain, vomiting and nausea associated with cancer treatments, and from fatigue.

IMPORTANT: Always use a registered acupuncturist and preferably someone with experience of working with people with cancer. And speak to your healthcare team before starting a programme of acupuncture or any other complementary therapy.

Fertility preservation

The loss of ability to have children is a major concern for young women with cancer. Preserving fertility may be possible for some of these women. Options regarding preserving your fertility should be part of the early discussions you have about your cancer treatment.

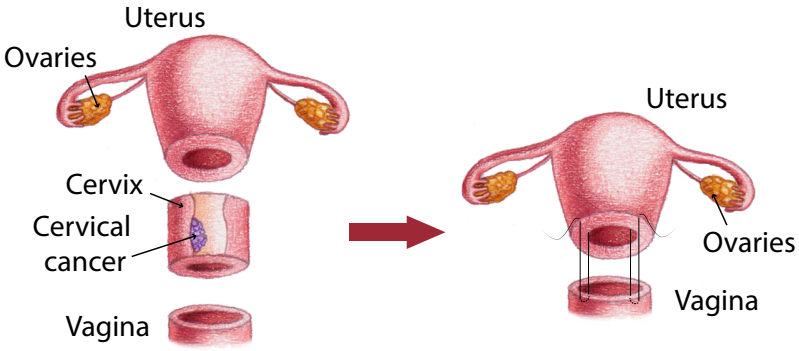
Always ask about your fertility options if future pregnancy is important for you. However, you need to understand that even if fertility preservation is possible, it may be time consuming or may not be appropriate for you if your cancer could spread quickly or is sensitive to the hormones used during the fertility treatment.

It is important to act quickly in cancer treatment and it should not be unnecessarily delayed.

Cervical cancer and fertility

If your cancer is small enough (less than 2 cm) and has not spread beyond the cervix (early stage), you may be able to have surgery to remove just the cervix and leave the rest of the womb behind. This is called **trachelectomy** and can be done through the vagina or through an incision in your abdomen; this is known as open (laparotomy) surgery.

What are the risks? While it is safe to treat the cancer in this way in most cases, women who have this kind of surgery have a higher risk of miscarriage, preterm births and the need for caesarean section delivery if they get pregnant in the future. Painful periods may also be a consequence, and you may experience difficulties getting pregnant naturally. You may need fertility treatment.



With even smaller tumours, you may be advised to have only a piece of the cervix removed. Your doctor will be able to advise if any of these treatments are an option for you.

Radiotherapy for cervical cancer. If you need radiotherapy to the pelvis as part of your cervical cancer treatment, you may have your ovaries repositioned (away from the pelvis) to avoid them being exposed to radiation and damaged. This is called **ovarian transposition**. This can be done at the time of your initial surgery or as a separate operation. The idea is to prevent early menopause so that your ovaries can be used later for collecting eggs for in vitro fertilisation (IVF) and achieving pregnancy in a surrogate womb if appropriate. However, the operation is not always successful.

Endometrial cancer and fertility

You may have found out about your cancer in the fertility clinic or during testing for heavy or irregular periods. In very early cancer of the womb, it may be possible to treat it with high doses of a progestogen hormone (or some alternative) to avoid or delay a hysterectomy. The hormone may be delivered via a hormone-bearing coil.

You will need follow up and a few biopsies and scans to make sure the cancerous cells respond to the hormones. If the cancer shrinks and disappears, your doctor may advise you to have fertility treatment to speed up achieving a pregnancy, if appropriate.

You may still be advised to have a hysterectomy after you give birth, as a definitive cancer treatment.

Ovarian cancer and fertility

For some younger women with epithelial ovarian cancer in one ovary, it may be possible to keep the healthy ovary. However, the surgeon usually cannot be sure that the cancer has not spread to your other ovary or your womb.

After surgery to remove the one ovary, you are likely to have further biopsies and regular follow-up scans as there is always a risk of a small cancer in the other ovary being missed or of the cancer coming back.

Unfortunately, not all types of ovarian cancer are suitable for treatment with this type of surgery.

Vulval cancer and fertility

Surgery for vulval cancer would normally not affect your fertility, although it may influence your sexual function (see page 23). However, if radiotherapy is used as part of your treatment, this may affect your ovaries (see pages 21 and 32).

Storage of oocytes and embryos

If fertility-sparing surgery is not appropriate or safe, some fertility treatments may be available to you. Your doctor will be able to refer you to a fertility specialist to discuss your options, which may include those listed in the table below.

Storage of oocytes* and embryos	
Procedure	**What it is**
Ovarian tissue retrieval and cryopreservation	The removal of parts of your ovaries to store at very low temperatures for future use
Ovarian stimulation and oocyte retrieval	The stimulation of your ovaries with hormones to produce eggs that are stored at very low temperatures for future use
IVF and embryo cryopreservation	The fertilisation of your own eggs with sperm to form early embryos that are stored at very low temperatures for future use. If your womb has been removed, surrogacy is necessary to achieve a pregnancy

*An oocyte is a cell from your ovary that can develop into an egg.

Egg donation

Egg donation may also be an option particularly if ovarian stimulation and egg collection have not been successful. These are eggs from another woman which are fertilised, possibly with your partner's sperm, and which then develop in your womb in the same way as a naturally occurring pregnancy. Using donor eggs is a major decision with its own implications and you should take your time to think about if this option is right for you.

When fertility preservation is not possible

While adoption is not strictly speaking a fertility-retaining option, it is a choice sometimes made by women in your situation.

Questions to ask your doctor about fertility preservation

Will I still be able to have children after my treatment?

Can I delay my treatment until after I have had a baby?

Is there a way I can preserve my fertility?

Which option is most likely to be successful for me?

What does this involve?

What are the risks?

Will any option guarantee that I will be able to have a child in the future?

If it is not possible to preserve my fertility, or if none of the options are successful, is there anything else I can do to have a baby?

Psychosexual support after gynaecological cancer

Sexual difficulties are experienced by many gynaecological cancer patients and can last long after treatment has finished. In the following pages, we discuss many of these difficulties, why they happen and some things you and your healthcare team can do to manage or lessen them.

One source of help and support that many women and their partners find extremely helpful is **psychosexual therapy**.

What is psychosexual therapy?

Open communication about sex and intimacy is important during your treatment journey, though it is rarely easy. Many of us are not used to talking openly about intimacy and it can be uncomfortable or embarrassing. A **psychosexual therapist** is trained to help people feel more comfortable talking about these deeply personal issues. As trained professionals they will not be shocked or embarrassed by anything you or your partner want to tell them.

A psychosexual therapist may also be called a **sex and relationships therapist** or a **sex therapist.** They may hold sessions in hospital clinics, in their own private practice or work with associations dedicated to helping couples with relationship problems.

> *"I think it's really important to prepare women a bit more for the effects that something like brachytherapy has and [to explain] how you can maybe change your outlook with the help of therapists and seek other things in life to satisfy yourself [after cancer]."*

Who can see a psychosexual therapist?

Anybody who is experiencing problems that relate to sexual health and wellbeing. You can be in a relationship or single, but if you have a partner, it is important that he or she also takes part. Sometimes therapists will offer hybrid sessions, in person and online at the same time, to make it easier for couples who cannot attend a session together.

Why is it important for couples to both take part?

Cancer has a profound effect on relationships. Your partner will have felt the shock of your diagnosis and the fear that cancer brings. After treatment, your partner is likely to be afraid of hurting you, or doing something that upsets you. Many partners say they feel helpless or powerless to make things better. Some partners find they cannot cope with what has happened and the impact of what has happened on the relationship.

We know that many couples do not talk openly about their sex life before cancer so talking about it *after* cancer treatment may feel impossible without the guidance and support of a therapist. Even if you and your partner had good lines of communication before your cancer, you may need the extra help that a therapist can give.

Is psychosexual therapy the same as counselling?

No. Therapy is more directive. Your therapist will give you (and your partner) homework to do. The aim of this is to help you reconnect with your body and, if you are in a relationship, to reconnect as a couple. What the homework will be depends entirely on your and your partner's needs.

Is psychosexual therapy just about sex?

No, not at all. Some women and their partners are not ready to or do not feel that they want to re-establish a sexual relationship. What they miss, however, is intimacy and connection. Psychosexual therapy is an approach that is tailored to your needs, your values and your wants, whatever they may be.

> *"It was around six months [after treatment] and we really had to kind of gear ourselves up [to have sex]… I wish that somebody had discussed it with both of us. It was mechanical rather than emotional, if you know what I mean. We just almost had to get it done."*

How can psychosexual therapy help me?

Psychosexual therapy can help you

- acknowledge the pain and fear you may be feeling
- come to terms with the grief you may be feeling
- express your feelings about the changes to your body
- express your feelings about the impact of those changes on your fertility
- express your feelings about the impact of those changes on your close relationships
- re-establish intimacy and connection with your partner
- find new ways to relate to your partner
- find new ways to express your sensuality
- reframe your identity as a woman.

Therapy can also help women with the use of post-treatment interventions, such as dilators (see page 29). Some women find these difficult or upsetting to use without support.

Psychosexual therapy can help you find relief from some symptoms of the menopause and can help with some of the side effects of treatment that involve your vagina or vulva.

Why is psychosexual therapy useful?

Healthcare professionals rarely raise the issue of sexuality with their patients. This is true not only of doctors, but also of nurses and other practitioners. The focus of a psychosexual therapist is on relationships and sexuality.

> *"I saw a therapist for nine months. The approach used was a bio-psychosexual social occupational one. Those nine months were critical to my recovery."*

Guide to words and phrases

Abdomen: The tummy area between the lower ribs and pelvis.

Adjuvant chemotherapy: Cancer treatment that people receive after they have received another therapy, such as surgery.

Advanced cancer: Cancer that cannot be cured. Treatment can sometimes slow or shrink advanced cancer.

Anus: The external opening of the rectum.

Biopsy: A procedure to remove a small piece of tissue from the body so that it can be examined under a microscope.

Bladder: The organ that collects and releases urine from the body.

Brachytherapy: A type of internal radiotherapy. A small radioactive material called a source is put into your body, inside or close to the cancer.

Cervix: The entrance or 'neck' of the womb, near the vagina

Chemoradiation: Having chemotherapy at the same time as radiotherapy.

Chemotherapy: The use of drugs to kill cancer cells or stop cancer from growing.

Dyspareunia: Pain during or after sex.

Dysuria: Pain or discomfort when peeing (urinating).

Endometrium: The lining of the womb (uterus).

External beam radiotherapy: The most common form of radiotherapy. A radiotherapy machine aims high-energy rays at the area of the body being treated.

Fallopian tubes: The pair of hollow tubes leading from the womb to the ovaries.

Fertility: The ability to conceive a baby (become pregnant).

Follicle: a fluid-filled sac in the ovaries that contains an immature egg..

Follicle stimulating hormone (FSH): a hormone involved in the development of the ovaries in women and the testes in men.

Gene: A gene is the basic physical and functional unit of heredity. Genes are made up of DNA.

Haemorrhoids: A medical term for piles.

Hot flush: A sudden feeling of intense heat, reddening (of face and chest) and sweating. Often a symptom of menopause.

Hormone replacement therapy: HRT.

Hysterectomy: An operation to remove the cervix and womb, and sometimes the ovaries.

Incontinence: Not having full control over the bladder and/or bowel.

Internal radiotherapy: Another name for brachytherapy.

Kegel exercises: Well-known exercises for strengthening the pelvic floor.

Labia: The lips of the vulva.

Laparotomy: An operation where the surgeon makes a cut into the abdomen to look inside the abdominal cavity.

Large intestines/bowel: The last part of the intestines.

Libido: Sexual desire.

Locally advanced cancer: Cancer that has spread into the neighbouring tissues.

Luteinising hormone (LH): A hormone that is involved in many processes in the body, including pregnancy, puberty, and ovulation.

Lymph nodes: Small, pea-shaped organs that are part of the lymphatic system.

Lymphatic drainage: A massage therapy to help the drainage of lymph nodes. Used to relieve lymphoedema.

Lymphatic system: An organ system that is part of the immune system.

Lymphoedema: Lymphoedema is a long-term (chronic) condition that causes swelling in the body's tissues. It can affect any part of the body, but usually develops in the arms or legs. It develops when the lymphatic system does not work properly.

Menopause: When your periods stop due to lower hormone levels. This usually happens between the ages of 45 and 55 but can happen because of medical treatment.

Menstrual cycle: The monthly process in which an egg develops and the lining of the womb is prepared for possible pregnancy.

Metastasis: When a cancer spreads to another part of your body from where it began.

Micronized progesterone: A type of progesterone that is identical to the progesterone produced in our bodies.

Mixed incontinence: Experiencing both stress and urge incontinence.

Mutation (gene): Changes in the DNA inside a cell.

Myometrium: The smooth muscle tissue of the uterus.

Neo-adjuvant chemotherapy: Cancer treatment that people receive as their main treatment, before they receive any other treatment.

Night sweats: Intense sweating

at night. Can be a symptom of menopause.

Oestrogen: Estrogen (US). A female sex hormone produced by the ovaries.

Oocyte: An undeveloped egg (ovum).

Ova: the plural form of ovum.

Ovum: female reproductive cell. Also called an egg.

Ovarian transposition: When ovaries are surgically displaced to protect them during radiation therapy to the pelvis.

Ovaries: A pair of organs (each about the size of an almond) in a woman's pelvis. They produce follicles from which eggs develop.

Ovulation: When an egg is produced and released as part of a monthly menstrual cycle (a period).

Palliative chemotherapy: Cancer treatment that can relieve the symptoms of the cancer but cannot cure the cancer.

Pelvic floor muscles: Layers of muscle which support the bladder and other organs in the pelvis.

Pelvis: The bony structure at the lower part of the abdomen.

Perimenopause: The time before your periods stop completely. It can last for a few years.

Perineum: The area of skin between the anus and the vagina.

Peritoneum: The tissue that lines the abdominal wall and covers most of the organs in the abdomen.

Postcoital bleeding: Bleeding from the vagina after sex (intercourse).

Progesterone: A hormone produced at ovulation.

Psychosexual: feelings or emotions that affect your sex life.

Psychosexual therapist: A professional trained to work with people and couples who have problems with their sex lives/ relationships.

Psychosexual therapy: Therapy for single people and couples who have problems with their sex lives/ relationships.

Psychosocial: feelings or emotions that affect your self-confidence and your desire to spend time with other people.

Radiotherapy: A treatment where

radiation is used to kill cancer cells.

Rectum: The final section of the large intestine.

Small intestine/bowel: Part of the digestive system, the small bowel is between the stomach and the large bowel.

Stress incontinence: Leaking urine when jumping or coughing.

Surgical menopause: When menopause is caused by the surgical removal of the ovaries.

Trachelectomy: Surgery to remove the cervix and sometimes part of the vagina. The uterus is left in place, so it is sometimes possible to have a baby after this operation.

Tumour: A mass/group of abnormal cells. A tumour is sometimes cancer, but not always.

Urethra: The tube connected to the bladder through which urine passes when it is released from the body.

Urge incontinence: A sudden need to pee (urinate).

Urogenital atrophy: A condition which most often occurs during and after the menopause when the lack of the female hormone oestrogen affects the vagina, urethra & bladder.

Uterus: The part of the body where a baby develops. Also called a womb.

Vagina: The canal leading from the vulva to the cervix.

Vaginal dilator: Used to gently stretch the vagina, when it has become narrowed.

Vaginal stenosis: When the vagina becomes shorter and narrower. A common side effect of radiation therapy.

Vulva: The area around the opening of the vagina.

Womb: Another name for uterus.

Useful resources

Cancer

Cancer Research UK
cancerresearchuk.org

GRACE (Gynae-Oncology Clinical Research and Excellence)
grace-charity.org.uk

Jo's Cervical Cancer Trust
jostrust.org.uk

Macmillan Cancer Support
macmillan.org.uk

Peaches Womb Cancer
peachestrust.org

Shine Cancer Support
shinecancersupport.org

Target Ovarian Cancer
targetovariancancer.org.uk

The Eve Appeal
eveappeal.org.uk

Trekstock
trekstock.com

Womb Cancer Support
wombcancersupportuk.weebly.com

Young Lives vs Cancer
younglivesvscancer.org.uk

Menopause

Daisy Network
daisynetwork.org

Femal (food supplement)
www.femal.co.uk

Female First
femalefirst.co.uk

Menopause Matters
menopausematters.co.uk

Menopause Support
menopausesupport.co.uk

Pelvic health

Easy Kegel App
easykegel.app

NHS Squeezy App
squeezyapp.com

POGP (Pelvic Obstetric and Gynaecological Physiotherapy)
thepogp.co.uk

Dilators, lubricants and vaginal moisturisers can be found in pharmacies or online, including at Menopause Matters.

Fertility

Shine Cancer Support
shinecancersupport.org

Human Fertilisation and Embryology Authority (HFEA)
hfea.gov.uk

General

Medical terms explained (gynaecology)
www.rcog.org.uk/for-the-public/a-z-of-medical-terms

Fast Facts for Patients

Oncology

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HEALTHCARE

Oncology

Fast Facts for Patients

Sexual and Reproductive Health After Gynaecological Cancer

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