

This booklet has been written by healthcare professionals and there have also been valued reviews and contributions from women affected by breast cancer.tage)T healt@@neance li@en

If you've had breast cancer and are wondering what your treatment options are for menopausal symptoms, this booklet is for you. You may have been told that hormone replacement therapy (HRT) is not an option for you, or perhaps you have not had the opportunity to discuss what your options are. This booklet covers: symptoms you might have, treatment options including HRT, the risks and benefits of treatment when there's a history of breast cancer, plus lifestyle changes to help you manage symptoms. The aim of this booklet is to give you the information to help you decide what is right for you in conversations with your health professional, and of changes you might want to make in the future.

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You have already experienced – or are currently going through – one of the hardest times you've ever had to face in your life. Whether your breast cancer and treatment occurred years ago, or is still happening now, you've already had to deal with a lot and there will have been times when you felt frightened and overwhelmed.

Hopefully, you're now ready to begin thinking about your menopausal symptoms and future health, and make some choices that have the potential to positively affect the rest of your life. Let's start with a bit of a recap on breast cancer and how it links to hormones.

## **Breast Cancer and Hormones**

Breast cancer is the second most common type of cancer in the UK and around 1 in 7 women will develop breast cancer over their lifetime<sup>1</sup>. Thankfully, in the UK, breast cancer survival has doubled in the last 40 years<sup>2</sup>. Breast cancer is a complex disease with many different types and the role of estrogen in breast cancer is still poorly understood.

When cancerous cells are examined after a biopsy or surgery, it's identified whether the breast cancer cells have receptors for estrogen or not. Knowing this information helps treatment to be planned. If the cells have receptors for estrogen, it's called estrogen receptor-positive (ER-positive) breast cancer, if they don't carry receptors for estrogen it's known as ER-negative breast cancer.

This feature of breast cancer cells is important when it comes to deciding on treatments for menopause symptoms. Knowledge about whether your cancer was ER positive or negative may influence your decision about whether to take HRT or not.

At the time of a cancer diagnosis, there is a lot of information to process. The prime focus will be – and should be – successfully treating the cancer. Other considerations are unlikely to be a priority at that time but what about life beyond breast cancer?

The many individuals who survive breast cancer may suffer with after-effects of treatment and develop menopausal symptoms which can have a big impact on their quality of life after breast cancer.

Depending on when your breast cancer was diagnosed, you may have been premenopausal (still having regular periods and no menopausal symptoms), perimenopausal (periods and hormone levels starting to change) or postmenopausal (more than one year after your periods have stopped). Maybe you were taking HRT when you were diagnosed with breast cancer and had to stop your HRT whilst undergoing treatment, or maybe treatments such as surgery, chemotherapy, radiation and hormonal therapy caused you to have an earlier menopause. Everyone will have a different journey and experience different menopause symptoms.

# Perimenopause and Menopause

It is not unusual for women to be told by their cancer care team that menopause may be a consequence of their treatment and because the focus at that point is on cancer treatment, very little further discussion is had. You will often be focused on surviving your cancer during this time, but when the treatments are over and it's time to pick up the pieces of your life again a different — and difficult — reality can hit, as you soon come to realise what menopause really means.

#### Hot ushes

This is a common symptom and the one most people have heard of. Hot flushes can come on suddenly at any time of day, spreading throughout your face, chest and body. They may last only for a moment or take several minutes; you might also sweat, feel dizzy, or notice your heart beating faster. It is believed to be down to your internal thermostat picking up on wrong signals (due to lack of estrogen) about whether you need to cool down or warm-up.

#### Night sweats

You might also wake up very sweaty in the night, even to the extent of making your nightwear and bedsheets quite wet.

## Mood changes

These include feeling teary, irritable, angry, withdrawn, low self-esteem – a whole range of emotions. It's often the one that bothers people the most, as it can make you feel so unlike your normal self. These feelings can be a normal reaction to your diagnosis and treatments for cancer, and in the adjustment phase afterwards.

## **Anxiety**

Having breast cancer will undoubtedly cause you to feel anxious at times and worried about possible effects of treatments, and the impact on your partner, or family and friends — and these are all entirely understandable. The menopause can also increase feelings of anxiety considerably, exacerbating the worries you already have. This might include worries about treatment for your menopausal symptoms, such as HRT.

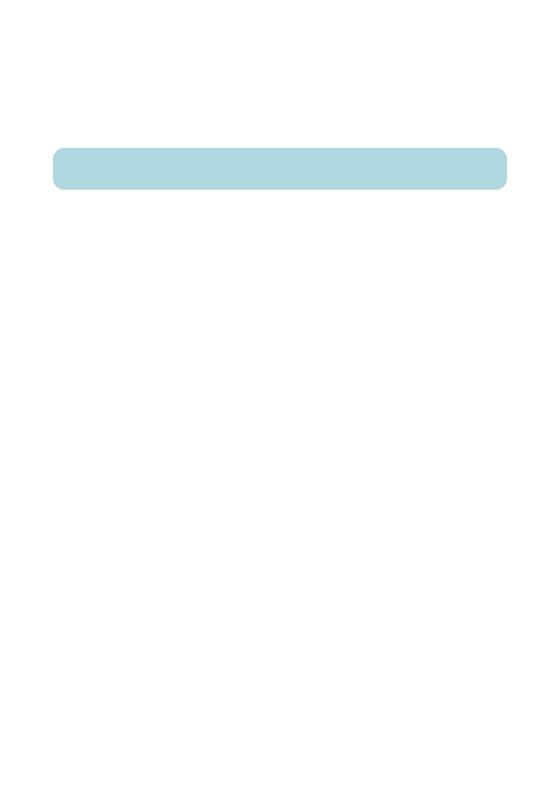
#### Fatigue and poor sleep

You may feel completely exhausted anyway, but tiredness can also creep up on you when you feel like you should be making a faster recovery from the cancer. It's common for sleep to be affected by menopause, either due to night sweats, needing to wee, feeling anxious or stressed, or a whole host of other possible reasons.

#### **Brain fog**

You may be familiar with 'chemo brain', well brain fog is the menopause equivalent. A lack of hormones can cause memory lapses, poor concentration, difficulty absorbing information and a feeling your brain is like cotton wool. Brain fog can be a real challenge, particularly at

# Relationships



Make adjustments at work — whether you go out to work or work from home, it's helpful to tell someone if there's any symptoms you're finding tricky to manage. You may need to adapt your workspace area, get a fan or window nearby, take more frequent mental pitstops or break up tasks differently. These little things can make a big difference to your comfort, focus and productivity levels.

## Consider non-hormonal treatments

### Herbal medicines

There are many treatments that some people find beneficial for their symptoms. However, specific remedies will not be described here as there is no good quality evidence to support their use. For example, NICE guidance on menopause diagnosis and management says women with a history of, or at high risk of, breast cancer that, should be advised that although there is some evidence that St John's wort may be of benefit in the relief of vasomotor symptoms like hot flushes, there is uncertainty about appropriate doses, persistence of effect, variation in the nature and potency of preparations, potential serious interactions with other drugs (including tamoxifen, anticoagulants and anticonvulsants)<sup>5</sup>.

## Talking therapies

There is evidence to support the use of cognitive behavioural therapy (CBT) to help a variety of symptoms and improve your quality of life.

#### Prescribed medications

Prescribed medications are usually offered for individuals if they do not want to, or cannot, take HRT, particularly to treat hot flushes. Examples of these are gabapentin or pregabalin and antidepressants, such as venlaflaxine. Studies show that there can be reduction in hot flushes with these medications but the unwanted side effects such as dizziness, weight gain, sleepiness and negative effects on sexual arousal can cause some women to stop taking these medications.

NICE menopause guidelines (NG101 and NG23) suggest some antidepressants, such as SSRIs, can be prescribed for individuals with breast cancer for relieving menopausal symptoms, particularly hot flushes. Be aware that if you take tamoxifen, then fluoxetine and paroxetine are not usually recommended.

In general, antidepressants have not been found to be of significant benefit for improving low mood and other psychological symptoms caused by a lack of hormones, as there is little evidence that they help. However, antidepressants can be beneficial for women with clinical depression.

# Helping your genital and urinary symptoms

Your vagina, vulva and surrounding tissues need estrogen to function well, and cancer treatments that are often given to women who have had breast cancer actually lower your estrogen levels, which can cause symptoms affecting these tissues and also your urinary tract. This (in addition to the menopause) can cause troublesome symptoms in some women. The symptoms can be so severe for some women that they can even affect normal daily activities including sitting, walking, wearing certain clothing and underwear, and it can also affect sleep. While many menopausal symptoms often improve over the years, symptoms of GSM tend to worsen with time.

If you've had (or are undergoing) treatment for an ER-positive breast cancer, your first choice of treatment for symptoms of genitourinary syndrome of menopause (GSM) would usually be those that don't contain hormones. Try and avoid using soap, shower gels, deodorants, or 'intimate' products on the area, instead use a gentle emollient wash, such as Cetraben®.

Panty liners, spermicides and many brands of lubricants can contain irritants. Tight-fitting clothing and long-term use of sanitary pads or synthetic materials can also worsen symptoms.

Vaginal moisturisers such as YES®VM, Sylk Intimate, or Regelle® can help hydrate your tissues and reduce soreness and discomfort throughout the day. Specialist lubricants for when having sex, such as Sylk, YES®OB or YES®WB can ease discomfort and make the experience more enjoyable. If you're using a barrier method of contraception, water-based lubricants are usually best.

These non-hormonal treatments may not be enough to manage severe symptoms however, and this is where you should discuss the option of using local vaginal estrogen or other vaginal hormonal treatments. By inserting estrogen into your vagina or on your vulva then you are providing the hormone directly to where it's needed most, without it being absorbed into your bloodstream.

Most women who have had breast cancer in the past can still use vaginal hormonal preparations as they are not absorbed into your body and the doses of these preparations are very low.

## Types of vaginal estrogen

Vaginal estrogen, also known as topical or local estrogen, is currently only available with a prescription, and there are three main ways to have it:

**Pessary** – The most common choice is to use a pessary, such as Vagifem®, Imvaggis® or Vagirux®. They are small like a tablet, and you insert it into your vagina, using an applicator or your fingers. You use it daily for the first 2 or 3 weeks, and then twice-weekly after that.

Pessaries are usually inserted at night time, so it can stay in place in your vagina for several hours

There is another type of pessary, Intrarosa®, which contains DHEA, a hormone that your body naturally produces. Once positioned in your vagina, the DHEA is converted to both estrogen and testosterone.

Cream or Gel — Estrogen creams, such as Ovestin®, are inserted inside your vagina on a daily basis for the first two weeks, and then twice-weekly after that. An applicator can be used to insert the cream into your vagina, plus it can be applied with your fingertips on and around your vulval area as well, which can be useful if you are experiencing itching or soreness in surrounding areas.

Blissel® gel is a lower dose option which has an applicator to insert the gel inside your vagina. It is used every night for three weeks, then twice a week after that.

Ring — If you don't fancy using pessaries, creams or gel on a regular basis, another option is to use a flexible silicon ring, such as Estring®. This is inserted inside your vagina and stays there to release a slow and steady dose of estrogen over 90 days. It needs replacing every three months, which you can do yourself, or a nurse can change it if you prefer. You can leave the ring in position to have sex or remove it and reinsert it afterwards.

Vaginal estrogen can really help with genital changes, discomfort and related symptoms; the estrogen helps restore your tissue back to how it was before. If left untreated, these symptoms tend to get worse over time so it's best to act early to prevent further exacerbation of the problem. Vaginal estrogen is a much lower and more diluted dose of estrogen than the type in systemic HRT.

Studies have not shown any risks associated with the use of long-term vaginal estrogen.

## Bene ts of vaginal estrogen

Less pain, soreness, itchiness and general discomfort

Maintains and restores natural lubrication

Maintains and restores 'stretch-ability' of

## Risks of vaginal estrogen

There is no evidence that suggests women using vaginal hormone treatment who are undergoing treatment for (or have a history of) an ER-positive or ER-negative breast cancer

are at an increased risk of cancer recurrence. This means that healthcare professionals can usually prescribe vaginal hormonal preparations to individuals with breast cancer, including ER-positive breast cancers.

Many menopause specialist clinicians are of the opinion that the risks of vaginal hormone treatments are likely to be low if you have had breast cancer (including ER-positive breast cancer), although long term data is unfortunately not available.

There is very little evidence that estrogen placed in your vagina is absorbed by the rest of your body, which suggests that if you take aromatase inhibitors you can also take vaginal estrogen if your symptoms are bothersome and non-hormonal options do not provide enough relief. However, these drugs do work in a different way to tamoxifen and again there is unfortunately no long-term safety data about this.

#### Be reassured

If you decide to try vaginal estrogen, do not be put off by the information that is packaged with your medication, it is not correct and should be rectified but unfortunately this change hasn't happened yet.

## Vaginal symptoms and intimacy

If you're having regular sex with a partner, try and be as open and honest as you can about how it feels. Moisturisers and lubricants can ease the soreness and vaginal estrogen can restore your tissues to feel more normal again.

The next section helps to explain more about the different types of HRT, including testosterone.

# Helping your symptoms with HRT

#### What is HRT?

HRT stands for hormone replacement therapy and is an umbrella term for the different hormonal treatments that people can take for the menopause. It usually contains the hormone estrogen — the key hormone that affects so many different parts of your body when you don't have enough of it.

If you take replacement estrogen, you need to take another hormone to protect the lining of your womb (if you still have one) and this is known as progesterone or progestogen.

There is a third hormone, testosterone, that you naturally produce, that can also be used as part of HRT.

## Ways of taking the different hormones

**Estrogen** — This is available in tablet form, but the safest way to take estrogen is through your skin, via a sticky patch, gel or spray (examples of brand names are Evorel®, Estradot®, Oestrogel®, and Lenzetto®). You will need to take it every day, and younger individuals (under 50 years) often need higher doses of estrogen to resolve their symptoms.

Progesterone — This is usually just for individuals that still have their womb and it's taken to counteract unwanted effects on your womb lining that can happen if you take estrogen. The body identical form is called progesterone which mimics the way natural progesterone works in your body, and the synthetic (chemically created) types are called progestogens. The safest type is micronised progesterone, known as Utrogestan in the UK, and it comes in a capsule form that is taken daily, often in the evening, as it can also have a mildly sedative effect. The capsule is usually swallowed but it can also be inserted vaginally. An alternative type of progesterone is via a Mirena coil which is a small plastic device, inserted in your womb that stays there for five years and is then replaced.

**Testosterone** — This comes in a cream or gel that you rub into the skin on a daily basis (known as Androfeme, Testim or Testogel). Many GPs do not prescribe this, so you may need to obtain testosterone from a menopause specialist. If your interest in sex, or ability to orgasm has dropped, and you have already been taking HRT for a few months testosterone replacement may be beneficial. Testosterone is not just a male hormone, your ovaries produce it too. After a few months, many menopausal individuals taking testosterone find their interest and enjoyment in their sex life resumes.

Many women find that it can also improve symptoms of fatique and poor concentration.

These three forms of HRT are called 'systemic' HRT, as they are absorbed into your bloodstream and make their way around your whole body. Estrogen receptor cells are everywhere: your brain, heart, skin, liver, bones, nerves, muscles, bladdO O muscles, blt coc2. EsBDCi3.29

The following quote is from Caroline, who went through breast cancer, surgery and chemotherapy and entered the menopause when she was 39:

"In hindsight, much of my anxiety around taking HRT was due to the symptomatic effects of the menopause. I couldn't think straight and needed time, the right information and guidance. In the end, small steps worked. Since going on HRT, my anxiety has dramatically reduced, and I can make clearer decisions that are driven by logic rather than fear."

### What are the risks of systemic HRT if I've had breast cancer?

It is not possible to quantify risks as they vary between different people and are likely to be different for different types of breast cancer in the past too. If you have had breast cancer, you should have been given an explanation of any potential individual risks when it comes to taking HRT, so you can weigh up the pros and cons of any decisions around possible treatment. What is important is that you are informed about the risks and benefits and how treatment might impact your quality of life, and that you feel you have enough information to weigh up and make a personal decision that is right for you. So, here's what is currently known about the risks of taking HRT if you've had breast cancer:

#### **Ductal Carcinoma in Situ (DCIS)**

You may have been told you have non-invasive breast cancer or DCIS. While this is the earliest form of breast cancer, it still requires treatment and will no doubt cause additional worry for you at times. If you think you might be perimenopausal or menopausal, many women consider taking systemic HRT for their symptoms and/or vaginal estrogen if they

#### **ER-positive breast cancer**

The best advice is to talk it all through with a healthcare professional who is an expert in treating people for the menopause after breast cancer. It is usually advisable to talk to a menopause specialist as well as a breast specialist oncologist to talk about your individual circumstances.

#### Aromatase inhibitors and tamoxifen

Tamoxifen is a selective estrogen receptor blocker (SERM). This means it blocks estrogen on some cells, including on the breast, but not on other cells. Tamoxifen is used in both premenopausal and postmenopausal individuals to treat breast cancer. Aromatase inhibitors are used to treat breast cancer in people who are post menopausal whose ovaries are no longer producing estrogen. Sometimes it is used in those who are premenopausal but only if their ovaries are 'switched off', which is usually done by a hormone injection. The purpose of taking aromatase inhibitors is to block your body from producing any estrogen anywhere in the body, (small amounts are produced elsewhere in the body apart from the ovaries). If you are taking an aromatase inhibitor and are experiencing dreadful symptoms then you could talk to your breast specialist about the possibility of taking tamoxifen or an alternative instead. This may lead to your symptoms improving.

#### The bottom line about risks

It is important to have a detailed conversation with health professionals about your own individual risk. Some women do choose to take HRT despite there possibly being some risks as they want to improve the quality of their lives. It is important than you have an opportunity to discuss any decisions regarding treatment with your healthcare professional and that you are comfortable with the decision. Shared decision making is really important and you should also be aware that you can change you mind at any time — so either stop or start treatment in the future. We are all unique and it's important that care is individualised.

### Risk of a blood clot with HRT

There is a small risk of a clot if you take the tablet form of estrogen, but taking it through the skin as a patch, gel or spray does not have any increased risk of developing a clot. If you decide to take replacement estrogen, through the skin is safer than tablets you swallow, especially if you've had a clot in the past or suffer from migraines.

#### What are the side effects of HRT?

Side effects with HRT are uncommon but might include breast tenderness, leg cramps or some vaginal bleeding initially after starting. If side effects do occur, they usually happen within the first few months of taking HRT and then they usually settle with time as your body adjusts to taking the hormones.

#### Other factors that increase your risk of breast cancer

Every day we make decisions which involve weighing up risks and benefits. Deciding whether to take HRT or not should be no different. If you're worried about the risk of HRT because you've had breast cancer, it's important to look at other areas of your life that increase your risk and how you can address these too, so that if you do decide to proceed with HRT you are minimising your overall risk as much as possible.

The lifestyle factors that increase your risk of breast cancer are: being very overweight (BMI of 30 or more), drinking alcohol most days, smoking, and a lack of physical exercise.

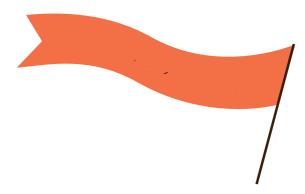
## Understand more to help decide the treatment right for you

Be your own advocate: being informed will mean you can have more rounded conversations with healthcare professionals about potential treatment options. Take time to read up on the menopause, know what the potential symptoms are and what the evidence says about HRT. Listen to podcasts, watch videos, hear advice from others going through it.

We understand that the decision you ultimately decide upon will have required a lot of research, thought and effort. People can often be judgmental and freely voice their opinions on whether you should, or should not, take HRT.

Make decisions about treatment with your doctor

In general, your best approach when talking to your doctor or other healthcare professional about your menopause is to clearly state your reasons for what you would like, explain what information has led you to this decision, and that you know what the associated risks might be but that it is still what you choose to do.



# Find support

The experience of going through cancer treatments and then finding out you're in the menopause can feel very isolating and may make you want to withdraw from friends and family and try and deal with things on your own. Although this is a very normal reaction, after a while it can often lead to feeling like everything is getting on top of you and you might struggle to cope. Find a family member or friend who is a good listener, doesn't judge

Here is a final quote from Mel, who decided to try vaginal estrogen several years after her breast cancer treatment finished.

"I recently made the decision to start using vaginal estrogen. Enough was enough. My symptoms were so severe and worsening, and it was really impacting on my quality of life. For me, it has been a great decision and it has made a huge difference. However, I don't regret not making the decision earlier, as I believe you have to make each decision in life based on the information available and how you feel at the time

— you can't look back with regret.

My point is, things can change, the balance can be tipped and that's ok.

The most important thing is being comfortable that it is the right decision for you. I can truly understand why women who have had breast cancer may choose to either have or not have HRT, either vaginally or systemically. But they should have the opportun 60ievcomfortable that 7 0 0 9.5

