



Newson Health

ovarian
cancer action

**HRT for those with high inherited
risk of cancer**

This booklet has been jointly produced by Dr Louise Newson and Ovarian Cancer Action.

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Ovarian Cancer Action is working towards a world where no woman dies of ovarian cancer. For more information on Ovarian Cancer Action and their work in this area visit www.ovarian.org.uk/brca

This booklet has been specifically produced for women who have a higher risk of gynaecological cancer compared to the general population. This is usually due to a significant family history of gynaecological cancer and/or a genetic test result showing they carry a fault in a gene that is known to increase their lifetime risk of certain cancers, such as BRCA1, BRCA2 or Lynch syndrome.

Women in this situation are commonly advised to undergo risk-reducing surgery in order to minimise their chances of developing gynaecological cancer. This involves having their ovaries and fallopian tubes removed, and women with Lynch syndrome also usually have their womb removed.

If you have questions about genetic testing, your risks and risk-reduction options, please see Ovarian Cancer Action's website www.ovarian.org.uk/brca

What is the Menopause?

The word menopause literally means when your periods stop. Meno- refers to your menstrual cycle and -pause refers to the cycle stopping. The medical definition of being menopausal is when you have not had a period for one year. A natural menopause occurs when your ovaries no longer produce eggs and, as a result, the levels of hormones called estrogen, progesterone

and testosterone fall.

A 'surgical' menopause is when there has been a medical intervention, (for example, surgery, radiotherapy or chemotherapy), that has removed the ovaries or stopped them from working normally. A surgical menopause usually brings on menopausal symptoms more suddenly than a natural menopause.

What is perimenopause?

The term perimenopause is often used to describe the time before a natural menopause when women experience menopausal symptoms but are still having periods. These periods typically

change during the perimenopause and may occur further apart or closer together; they can be more irregular and heavier or lighter in flow during the perimenopause.

What is Hormone Replacement Therapy (HRT)?

Hormone replacement therapy (HRT) is a treatment that replaces the hormones your body will no longer produce once your ovaries are removed. It includes the hormones estrogen, often progesterone, and in some cases testosterone, to relieve symptoms of the menopause and reduce your risk of developing conditions such as osteoporosis and heart disease in the future.

HRT is the most effective treatment available to relieve symptoms caused by the menopause such as hot flashes, night sweats, mood swings, brain fog, vaginal dryness and bladder symptoms.

Estrogen is a very important hormone and has vital roles in many different systems in your body including your brain, bones, heart, skin, hair and vagina. Taking HRT replaces the estrogen that your ovaries were producing before your

operation. You should take estrogen for ever to replace your low level; you do not need to stop taking it after a certain length of time.

Progesterone is naturally produced in the body primarily to help regulate the menstrual cycle. It is used as part of HRT for women who take replacement estrogen and still have a womb. Estrogen thickens the lining of the womb and when it is taken as part of HRT, there is a small risk that these 'over-active' cells could turn cancerous. Progesterone (or progestogen) helps keep the lining thin and reduces the risk of uterine (womb) cancer. Progesterone is usually taken as an oral capsule. Some women may be offered a Mirena coil which can be used as the progestogen part of HRT. This lasts for five years and can then be replaced with a new coil if needed.

If you still have your womb and want to take replacement estrogen, you will usually be advised to take a progestogen too, to minimise the risk of uterine cancer.

Testosterone is not just a male hormone, in fact, women produce four times the amount of testosterone than estrogen. The vast majority of testosterone is produced in your ovaries; after your operation you will experience a huge reduction in the amount of testosterone in your body. As a result, you may find that your mood, energy, concentration and also sex drive are negatively affected. Taking estrogen can help but it is often replacement testosterone that significantly improves these particular symptoms.

Testosterone is usually given as a gel

or cream that you rub into your skin. It can sometimes take a few months for the full effects to work in your body. There isn't a licensed preparation of testosterone for women in the UK currently, but there are ways of having it: there is a form of male testosterone which can be prescribed on the NHS, and privately, there is a female testosterone cream called AndroFeme, that is widely used in menopause specialist clinics.

There is currently no recommendation for when you should stop taking testosterone. It is common to have a blood test to ensure the hormones stay within the female range. The dose of testosterone is very low, and it does not increase your risk of developing facial hair, or changes to your voice or skin.

HRT and risk of breast cancer

There have been several scare stories in the media over the last twenty years around HRT and cancer - particularly breast cancer. This has resulted in many women being scared and put off from taking HRT, despite suffering with debilitating menopausal symptoms, as well as facing an increased risk of diseases, such as heart disease and osteoporosis (bone-weakening disease).

The negative connotations with HRT are largely due to a research trial that was published in 2002 (called the Women's Health Initiative Study) which was misrepresented in the media and the medical press. Many women involved in this trial were in their 60's and were taking a type of HRT that is not often

prescribed. Subsequent studies – including a thorough analysis of the WHI study - have shown how safe and effective HRT is for most women.

The type of HRT that is suitable for you will depend on various factors, such as your medical history and existing conditions, whether you still have a womb (uterus), and if you are still having periods. Your actual risk of developing breast cancer depends on many factors including age, family history and your general health, and not on whether you take HRT alone. That is why it is crucial to discuss your individual circumstances with your doctor and/or a menopause expert.

Studies have shown that women who take estrogen-only HRT actually have a lower risk of developing breast cancer. Taking combined (estrogen and progestogen) HRT may be associated with a very small risk of developing breast cancer. Research has shown that this risk reduces in women taking a natural progesterone called 'micronised progesterone', which is derived from plants. The risk of breast cancer when taking any type of combined HRT is very low. Women who are obese or drink a large glass of wine a night, actually have a far greater risk of developing breast cancer than a healthy woman taking any type of combined HRT.

Reassuringly, there has never been a study that shows women who take HRT have a higher risk of death from breast cancer. In fact, women who have had a full hysterectomy and take estrogen-only HRT have a **lower** chance of having breast cancer and a **lower** risk of death from breast cancer, than those who don't take any HRT.

For the majority of women starting HRT under the age of 60 years, the benefits of HRT really do outweigh any risks. This means that it is safe to take HRT and it can provide you with additional protection for your future health, especially for your bones and heart.

HRT for women with BRCA1/2 or Lynch syndrome

If you have a genetic mutation such as BRCA 1 or 2 or Lynch syndrome, you already have a high lifetime risk of cancer and taking HRT does not usually increase this further.

When you have surgery to remove your ovaries, you immediately go into a surgical menopause because your body no longer produces estrogen, progesterone and testosterone. Most women that take this step as a risk-reduction measure, will face menopause at an earlier time than the average age of a natural menopause - which is 51 years.

When making decisions around risk-reducing surgery and the consequences of removal of the ovaries, women often consider symptoms of the menopause but there are also health risks associated with the menopause in the long term, such as an increased risk of developing

heart disease, osteoporosis, type 2 diabetes and dementia.

As well as improving symptoms, HRT lowers your future risk of developing these diseases. Even if you do not experience many symptoms from your surgical menopause in the short term, it is worth considering the long-term impact of having low hormones on your health in the future, and how HRT can minimise these risks.

Current menopause guidelines advise that women with high-risk genetic mutations having risk-reducing surgery to remove their ovaries - before the age of the natural menopause - should be offered HRT until at least the age of 51. This is because of the health risks of having low hormones. Many women then continue to take HRT for ever in view of the many health benefits HRT gives to women.

HRT for women with a history of breast cancer

Unfortunately, there is limited evidence regarding the benefits and risks of taking HRT in women with a past history of breast cancer. As a general rule, a woman who has had hormone receptor negative cancer can usually take HRT.

If the cancer was estrogen receptor positive (ER+), HRT needs to be considered on an individual basis. Some women who have had ER+ breast cancer really struggle with their symptoms and menopause specialists sometimes give a low dose of HRT if alternatives have not helped - being fully aware that it is not

known whether or not this has future risks. Many women in this situation are willing to accept this unknown risk for an improved quality to their day-to-day life, as well as receiving the health benefits for their future health.

Whatever type of breast cancer a woman has had in the past, she can usually use vaginal estrogen treatments to help symptoms of vaginal discomfort and dryness, and bladder symptoms (see section on genital and urinary symptoms for more details).

HRT for women with a history of ovarian cancer

Women who have had ovarian cancer in the past can usually take HRT. There are some types of ovarian cancer that are estrogen receptor positive, therefore, it is best to speak to your oncologist and find out whether you had this type of ovarian cancer or not. If you did, the same advice applies as with ER+ breast cancer and healthcare professionals need to weigh up the benefits and potential risks to

make decisions on a case-by-case basis and take your views into account.

Other women who have had ovarian cancer in the past can still safely take HRT. There is no good quality evidence to show that women taking HRT have an increased risk of developing ovarian cancer - which is very reassuring.

Types of HRT and ways to receive it

You can read in detail about the different types of HRT, and how to use them in a

series of booklets and factsheets available on www.menopausedoctor.co.uk

HRT for women who do, and do not, have a uterus

It is important that woman receive individualised advice on what is most suitable for them, based on their own medical history.

Women who have had their fallopian tubes and ovaries removed - and *still*

have their uterus - usually need to take a progestogen or progesterone too. This is to help maintain the health of the uterus, keep the lining thin and minimise the risk of uterine cancer. The safest form of progestogen is 'micronised progesterone'. This can be taken in a tablet daily, or via

having a Mirena coil inserted into the uterus, which lasts for five years.

If a woman has had her ovaries, fallopian tubes *and* her uterus removed (a surgery often abbreviated to TAH & BSO), she doesn't usually need to take a progesterone. Women without a uterus

can usually take estrogen-only HRT.

Women who take any type of HRT can also have their testosterone replaced as well, if they are struggling with persisting lack of energy, concentration and reduced sex drive after a few months on estrogen.

When to start HRT

There is no need to wait until you have symptoms of surgical menopause before starting HRT. The earlier you start, the better it is for your bones, heart and brain health. Ideally, you will have had an

opportunity to discuss surgical menopause and HRT with your medical team in advance of your surgery, and make a plan that you are happy with ahead of time.

Getting the dose right

It is important that a woman has enough estrogen in her HRT to improve her symptoms and also reduce the long-term health risks of the menopause. Many women come to the conclusion that HRT has not helped so they give up taking it, but often, once a woman is on the right dose for her, real improvements do happen. Women often find they need to change their dosage over time, so it is important to have regular reviews with a healthcare professional if you are taking HRT.

The best way to monitor whether your dose is correct is to closely track

your symptoms. There is a recognised menopause symptom questionnaire known as the 'Greene Climacteric Scale' which can be found online, or you can easily keep track of symptoms by using the free Balance menopause support app (www.balance-app.com).

Even if you know for certain that you are in the menopause (because you have had your ovaries removed), it is a good idea to track your symptoms to measure the effectiveness of the HRT you are taking and whether you need to make some small changes to your HRT type or dose, in discussion with your doctor.

HRT in younger women

Younger women often need a higher dose of HRT because their bodies are designed to use more - and therefore need more - hormones. Some women find they need higher doses because their metabolism is faster.

Although there are maximum licensed

doses, it is still safe to use higher doses than this. Some younger women find they need 2 or 3 patches together, or more pumps of gel or spray, to fully improve their symptoms, so it is really important to tell your doctor or healthcare professional if you feel your symptoms are creeping back.

Usefulness of hormone blood tests pre-surgery

Some women are interested in having 'baseline' hormone checks before they have surgery to find out what their natural levels are while they still have their ovaries, in order to match these levels with the use of HRT after surgery. This is not something usually advised because:

a) hormone levels fluctuate greatly on any given day and are therefore not often reliable

b) home 'finger prick tests' can be very unreliable, so you could be trying to 'match' your hormone levels to a number that is not actually accurate

If you are still having symptoms after taking HRT, you may be offered a blood test to establish whether you are adequately absorbing the estrogen or you need a higher dose. It may be that the patches are not sticking correctly, or the gel is sliding off your skin and is not being absorbed properly.

When to stop taking HRT

NICE guidelines state that a woman experiencing an early menopause should be offered HRT until at least the age of 51. Beyond this age, women can continue to take HRT so long as the benefits outweigh the risks. For most women, the benefits outweigh the risks for the long-term and it is not the case that you have to stop taking HRT at a certain age. This

means you can usually take HRT for ever.

It is important to note that a lack of symptoms is not an indication that you do not need HRT anymore. Symptoms often return when HRT is stopped and even if they do not, the risks to your bone, brain and heart health continue to be an issue for the rest of your life.

Women who had risk reducing surgery several years ago but were not offered HRT

You are never too old to start taking HRT, or too many years past the menopause to gain benefit. We know from the available evidence that people who start HRT within 10 years of the menopause obtain the most benefit from taking HRT. Older people still receive benefits from taking HRT even if it has been more than 10 years since their menopause.

As mentioned, even if you have no

symptoms, it is still worth considering taking HRT for the health protection factors it offers for your bones and heart health. Regardless of the age they start, many women find that their quality of life improves when taking HRT.

Take a look at the factsheet 'Starting or continuing HRT many years after your menopause' on the menopause doctor website for more information on this topic.

Difficulties with getting a prescription for HRT

You should always try and speak with your GP or nurse regarding starting HRT - on more than one occasion if needed - or ask to see another doctor within your practice if there appears an initial unwillingness to prescribe it. Prepare your thoughts in advance and consider taking someone with you to help support you during the appointment.

You can download information from the Menopause Doctor website to take with you. You might find it useful to write your GP a letter which includes all your

thoughts and the information you have found out. See if there is an NHS menopause clinic in your area and ask for a referral to it.

If you still don't feel your wishes are being considered appropriately, you can ask to change GP practice and enquire whether there is a doctor at the new practice with a special interest in the menopause. Many women see a menopause specialist privately to obtain the right advice and treatment.

Bone health

A lack of estrogen over time can lead to your bones weakening and it increases the risk of developing osteoporosis and sustaining fractures to your bones from even a mild knock or bump.

HRT protects your bones from the weakening process and reduces the risk of osteoporosis. An additional way to look after your bones is to ensure you have enough calcium in your diet and to take a vitamin D supplement. Doing regular weight-bearing exercise is also important and activities that impact on your joints such as brisk walking, running, racquet sports, ball sports and aerobics are also very helpful.

You can measure your bone strength (bone density) by having a DEXA scan. It

can be useful to monitor bone density over the years following your surgical menopause. The NHS guidelines for DEXA scans state that if a woman has an early menopause - before 40 years old - they should have a baseline DEXA scan and then repeated scans every 3-5 years.

However, for women whose menopause was due to risk-reducing surgery you may not always fulfil the NHS criteria for a DEXA scan. The NHS criteria is based upon a measurement called a FRAX score, which assesses your individual risk factors for osteoporosis. It will provide a numerical level of risk, and those with a high risk will be offered a DEXA scan on the NHS. If you do not meet the criteria, you could source a DEXA scan privately if you wish.

Genital and urinary symptoms of the menopause

Around 80% of women who have gone through the menopause will experience symptoms related to vaginal dryness, and some level of disruption to their urinary function. Sadly, studies have shown that only around 7% of women with these symptoms receive adequate treatment.

The vagina is lined with cells that respond to estrogen. When there is a lack of estrogen, there is less lubrication, less blood supply to these cells, less of the 'good bacteria' that helps fight infection, and the lining of the vagina often becomes thinner and less stretchy. These symptoms can lead to soreness, discomfort, itchiness and pain during sexual intercourse, when using tampons, or when having vaginal examinations (such as cervical screening). The soreness or itchiness can occur around the vulva area as well and there may be more frequent episodes of thrush.

In addition, the lining of the bladder and urethra becomes thinner and more prone to infections like cystitis; you may need to pass urine more frequently or have occasional leaks or accidents.

These symptoms may occur very soon after entering menopause, or for some, it may happen years later; so it is worth being aware of what to look out for. There is very effective treatment for this particular set of symptoms in the form of 'local' estrogen. This refers to estrogen that you apply directly into the vagina and it is not the same as the HRT we have described so far.

Vaginal estrogen comes in the form of a pessary, cream, or gel that you insert (with the aid of an applicator if needed) on a daily basis initially, and then usually 2-3 times a week thereafter. Alternatively, there is a flexible, silicon ring called an 'Estring' that is inserted into the vagina and has a slow release of estrogen over a 90-day period; it needs replacing every three months.

Local estrogen is very effective at bringing relief from these uncomfortable - and often embarrassing - problems but if you wait until symptoms are more severe, it will take longer for the estrogen to have a noticeable effect, so it is important to treat genital and urinary symptoms as soon as possible.

Women who cannot have HRT for clinical reasons can still use local estrogen treatments in the vagina, and this is true even for those who have had ER+ breast cancer.

Once you need local estrogen for genital and urinary symptoms, you will need to use it forever. When symptoms become troublesome, they do not resolve of their own accord. It is perfectly safe to use local estrogen alongside HRT.

Vaginal moisturisers can also be particularly helpful at relieving discomfort throughout the day and non-hormonal lubricants can be useful for relieving pain during intercourse. Pelvic floor exercises are also very useful for strengthening the muscles and reducing urinary leaks or incontinence.

Alternative medications to treat menopausal symptoms

Antidepressants are sometimes given to help with sweats and hot flushes, but they do not help the low mood caused by a lack of hormones and many women do not tolerate the side effects of these types of medication very well.

Gabapentin (usually used to treat epilepsy and nerve pain) and Pregabalin (usually prescribed for epilepsy and

anxiety) can help with night sweats and hot flushes, but these also have some unpleasant side effects so need to be discussed with your doctor.

Some women find acupuncture, hypnotherapy and cognitive behavioural therapy (CBT) beneficial for improving menopausal symptoms.

Maintaining good health through the menopause

If you are having planned risk-reducing surgery, it is a useful opportunity to take stock of your lifestyle and make sure you're in the best health to prepare for the onset of the menopause.

Look at ways of improving your diet to ensure it is friendly to the health of your gut, that it contains plenty of fruits and vegetables, is low in red meat and processed foods (which are often full of sugar and salt), and try and make sure it contains plenty of calcium and vitamin D for your bones.

Smoking and alcohol can worsen symptoms of the menopause and negatively affect your mood and quality

of your sleep.

Regular aerobic exercise is essential for the health of your heart, blood vessels, and blood pressure, and exercise that is weight-bearing and impacts on your joints will help keep your bones strong. Frequent exercise and time spent on activities that you find relaxing and enjoyable will have great benefit to your mood and emotional wellbeing.

For more detailed information on living well through the menopause check out the resources section and select 'booklets' on the menopause doctor website.

About Ovarian Cancer Action

Action. One third of our name and 100% of what we're about.

One woman dies in the UK from ovarian cancer every two hours. Although five-year survival rates for ovarian cancer are improving, other cancers, such as breast cancer, had better survival rates two generations ago than ovarian cancer does today. We're here to change all that. And we're following two routes to achieve that change: awareness raising and scientific research.

Raising awareness for the quickest impact

We're campaigning to increase awareness and improve understanding of symptoms among the public and GPs. The symptoms of ovarian cancer can easily be attributed to other, less serious conditions such as IBS, or even to the menopause, but the sooner ovarian cancer is diagnosed the better the chance of survival. So education is vital. And we know it's where we can make the quickest impact.

Funding research for the biggest impact

The biggest impact we can make comes from our main area of focus: scientific research. Over the last fifteen years, our efforts to fund and facilitate the very best ovarian cancer research have achieved dramatic results. But, of course, there's more work to be done. We're now committed to funding the next generation of research and to accelerating progress in three main areas: preventing the disease, diagnosing it early, and developing effective, personalised treatments. We believe this approach will help more women survive ovarian cancer than ever before.

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Ovarian Cancer Action

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