

Premature Ovarian Insufficiency (early menopause)

Information for young women who have received treatment for cancer



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Introduction

This information has been developed by young women who are going through, or who are at high risk of going through, Premature Ovarian Insufficiency (POI) in collaboration with professionals from cancer, endocrinology, gynaecology, menopause and psychological specialities.

This booklet is aimed at young women (aged up to 40) who may be at higher risk of or going through POI (often referred to as early menopause) due to a cancer diagnosis and/or cancer treatments. It provides information around POI, including symptoms, management of POI and places to go for help and support. If you have any questions about this information or need any further support after reading it, please get in touch with the team treating you.

Early menopause and Premature Ovarian Insufficiency (POI)

Menopause usually starts in women around the age of 45-55 years old and is when menstrual periods stop, and natural pregnancy can no longer occur. At this stage no further eggs are produced by the ovaries; egg reserves are depleted, and egg quality is reduced.

Early menopause can occur between the ages of 40-45 years old (around 1 in 100 people experience this) and may be as a result of a family genetic predisposition. If the ovaries stop working and menopause happens before the age of 40 this is called Premature Ovarian Insufficiency (POI) or premature menopause.

There are a number of causes of POI including genetic and auto-immune conditions. It can also occur as a result of cancer treatment; for example, surgery to remove the ovaries (and sometimes also the uterus), as well as certain

chemotherapy drugs and radiotherapy that includes the ovaries within the area (known as the field) of radiotherapy.

This booklet gives information on POI due to cancer treatment and the impact this can have. When a person goes through natural menopause it can be distressing but is expected and usually happens over a fairly long period of time. It is different for younger people with cancer undergoing certain treatments, as POI is often a less recognised or talked about outcome of treatment.

The symptoms of POI can be mistaken for side effects of treatment or even treatment relapse. Going through this can be confusing and upsetting and it is important that you speak to your treating team if you are concerned about symptoms. Your team can run some tests to check and advise on how best to manage your symptoms.

Silence and stigma around menopause can make something that affects so many women still difficult to talk about. Ideas like 'menopause is a normal part or life' or that 'you should get on with it without medication or support', can make it feel hard to talk about your experience of POI or to ask for help. You may also have family members or others around you who have or are experiencing natural menopause, who may try to be helpful but who can say things that aren't relevant to your experience.

Going through POI can feel isolating and may make you feel like you are the only one going through this. When POI occurs it can be difficult knowing who to turn to and ask for advice. The aim of this booklet is to give you some answers to the common concerns that you might experience as a result of developing POI.

What do the ovaries do?

The ovaries produce hormones, (oestrogen and progesterone and testosterone), along with eggs (oocytes) that are released during a mid-point in a woman's menstrual cycle. These eggs can be fertilised with sperm which can lead to pregnancy. If the ovaries are removed or damaged this can no longer happen and the hormones and eggs are no longer produced. When there are no eggs that can be released and fertilised, a woman is no longer able to get pregnant. As the hormone production also stops there are a number of symptoms and physical changes that can occur as a result of this.

What do hormones do?

The hormone oestrogen has many functions including helping produce lubrication and thickening of the vaginal walls. A lack of this hormone can lead to vaginal dryness and thinning of the vaginal walls. This can make sexual intercourse painful or difficult. Oestrogen also has a role in the breakdown of fat in the body and a loss or reduction of oestrogen can lead to weight gain and abdominal bloating.

Oestrogen is also important for increasing and maintaining the strength of bones. As oestrogen levels drop bones become thinner and more likely to fracture. Young women (below 40 years of age) are much less likely to break a bone compared to older women even if their oestrogen levels are low. Oestrogen can also play an important role in cognitive functions (perception, attention, decision making and language comprehension) and memory as well as maintaining a good heart health. A long term effect of POI can be that you are at higher risk of heart conditions such as coronary heart disease or cognitive dysfunctions such as dementia.

Low oestrogen levels can also result from a reduction in secretion of luteinizing hormone (LH) and/or follicle-stimulating hormone (FSH) which are gonadotrophins from the pituitary gland (situated at the base of the brain). Gonadotrophins are any hormones that stimulate the gonads (ovaries/testis), or sex glands, to carry out their reproductive functions. For example, LH and FSH are required to stimulate the ovaries to produce oestrogen.

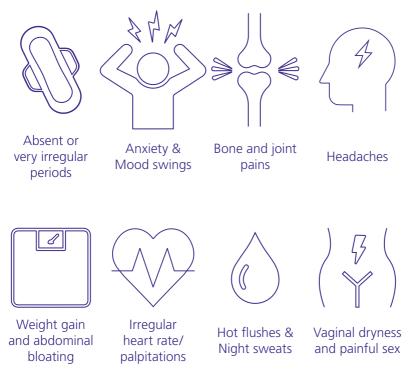
Low gonadotrophin levels can occur as a result of tumours of the pituitary gland, or near to the pituitary gland; surgery for these tumours or radiotherapy treatment involving the pituitary gland.

The symptoms of low oestrogen can be the same as for ovarian insufficiency and management with HRT may be recommended.

Young people with pituitary gland insufficiency, rather than ovarian insufficiency, have the potential for utilisation of pituitary hormones to stimulate the ovaries to produce eggs. You will need to speak to the team treating you – who can refer you to the endocrine and fertility services required in this situation.

It is important that young women going through POI are aware of these long-term effects, so they can get early access to advice and support around these issues. Please speak to your treating team about any worries or concerns that you have.

Common symptoms during POI



Further information on common symptoms of menopause can be found at www.ukmeds.co.uk/blog/what-are-the-34-symptoms-of-menopause. You should always speak to your treating team about any symptoms you experience as they will be able to offer you advice, and direct you to the right place offering support.

How to manage POI (early menopause)

POI symptoms can be managed through changes in lifestyle. This can include maintaining a balanced diet, getting regular exercise, getting enough sleep, managing stress and cutting down or cutting out alcohol and/or smoking.

Diet

Diet and nutrition can be essential in minimising some menopausal symptoms. A good balanced diet and increasing the amount of calcium and Vitamin D into the diet may help strengthen bones. Calcium can be found in food such as milk, cheese.

Some Omega-3 (good fats) found in fish have shown some benefit against hot flushes. Trying to eat well is important. Further information on the facts around menopause and diet can be found at www.bda.uk.com

Exercise

Exercising for 30 minutes a day (or whatever you can manage) can help to reduce feelings of stress, maintain a healthy weight and improve your general wellbeing. Any form of exercise can help and finding something you enjoy a bit more might help you to maintain your exercise regime.

It may be difficult to remain active but try to do your best and remember to recognise what your physical condition allows you to do.

Sleep

While total sleep time may not suffer during POI, the quality of sleep usually does. Hot flushes may interrupt sleep and frequent awakenings cause fatigue the next day. A way to combat this can be to follow a regular sleep schedule.

A sleep schedule could include going to sleep and getting up at the same time each day as well as avoiding naps as it may keep you awake at night.

Here are a few tips on how to sleep better during menopause:

- Maintain a regular sleep pattern and ensure there is sufficient time to wind down before bed
- Keep a cool temperature in the bedroom and use light, cotton bed linen and/or nightwear
- Try not to raise body temperature before bed so steer clear of large, late night meals and spicy food
- Avoid caffeine
- Limit computer and phone time in the evening and an hour before bedtime

Further information on the sleep and menopause can be found at www.sleepcharity.org.uk

Healthier lifestyle

Cutting down on or cutting out smoking and alcohol may help to reduce the symptoms of POI. Some women find that drinking alcohol makes hot flushes and sleep disturbances more common however this is different for everyone.

Managing your stress levels may also help to reduce symptoms of POI. Practice relaxation techniques, meditation or mindfulness to help reduce stress and worry. If you are unsure on how to do this or would like some guided sessions you can download apps such as Headspace to your smart phone. Speak to your treating team to see if they know of any local organisations that may be able to support you with this.

Medications

Hormone Replacement Therapy (HRT) is a type of medication or medications that can help to replace the hormones missing as a result of menopause.

Hormone Replacement Therapy (HRT) in POI should be given by a specialist team with experience of this, who will be able to advise you about the most appropriate form of treatment.

The main aim of HRT is to replace the missing oestrogen and progesterone hormones, which will help relieve many of the symptoms of menopause. It is also likely that HRT will protect against heart/blood vessel disease and improve bone density.

Progesterone is used to keep the lining of the womb thin. Without progesterone, oestrogen therapy continues to stimulate the lining of the womb which can build up and cause the cells to become abnormal which can lead to womb cancer.

Progesterone can either be given in cycles, which will cause a regular withdrawal bleed or continuously, where there will be no bleeding. In women who have had their womb removed (and other specific situations), progesterone is not required.

There are many different forms of HRT and HRT regimes. They can be given as tablets, patches, gels or pessaries. Some women choose to use the combined oral contraceptive pill rather than traditional HRT, as this can be particularly useful if pregnancy is still a possibility. It does, however, contain higher doses of synthetic oestrogen which can increase the risk of side effects.

HRT may not be suitable for everyone. This might be because you have or had a cancer that was hormone

sensitive, or because you have underlying medical conditions that would make HRT unsuitable for you to use. Some people also develop side effects from the HRT and cannot tolerate it. In this situation other medicines/treatments may be available to you. Please speak to your treating team about this.

Low levels of testosterone can occur in POI, this hormone is important for sexual function, and helps with desire and arousal. Under the careful monitoring of a menopausal specialist it may be suggested to have skin patches if required.

There are many supporters for alternative therapies, but it is important that you speak to your treating team about any of these before you try them. Other therapies may have an effect on any medication you are currently taking. Your treating team will have the best knowledge around your own circumstances and will be able to advise you.

Psychological impact

The psychological impact of going through POI can be devastating. Alongside the physical side effects and periods stopping, the issues arising around loss of fertility and your ability to become pregnant and carry a child can be overwhelming.

Psychological and emotional symptoms are common around the menopause, Anxiety, depression, sadness, difficulty concentrating, the feeling of overreacting to minor upsets, anger and irritability, forgetfulness and mood swings are all typical problems. You may experience some of these symptoms right away or even months or years later. It is important that when you do experience these that you get in touch with your treating team who can offer support or advise you on the right place for support.

It is important that you tell your treating team about how you are coping with your POI diagnosis. You are going through a lot, you may be experiencing loss and grief in many ways, and you should seek help and support. You can be referred to a counsellor, in some instances a specialist menopause, fertility counsellor, or a clinical health psychologist working with your treating team.

You may also find support from other young women going through a similar experience as you. The Daisy Network is a charity that specialises in POI and can offer general support. Further information on support available from this charity can be found at www.thedaisynetwork.org

Fertility and pregnancy

POI is associated with the depletion of eggs in the ovary. It can be very difficult to become pregnant naturally when this happens. In many cases however (except after surgical removal of the ovaries), the ovaries decline over time and there may be a short window where pregnancy is possible. This can be very difficult from a psychological point of view but there are many sources of support. Please speak to your treating team about a referral for specialist support around fertility and pregnancy.

If your ovaries stop working but your womb (uterus) is still intact, then it may be possible to carry a pregnancy using implanted fertilised eggs. This may be with your own eggs if they were stored prior to treatment, or by using donor eggs. This may be more difficult if you had radiotherapy that included your pelvic area. You should be referred to a fertility team with expertise in treating patients who have had cancer to discuss these options. Further information on POI and in vitro fertilisation (IVF) can be found at blog. scrcivf.com

Unfortunately, sometimes it is not possible to have a pregnancy yourself, but there may be other options that can be explored alongside the fertility team. Other options to become a parent may include surrogacy or adoption. You can be supported to look at your options and make decisions that are right for you.

Please speak to your treating team about information around getting pregnant, how long you should wait to conceive and the implications a pregnancy may have on you after your treatment. Your treating team will be able to give you more information around the egg retrieval process and the timescale and any funding available for this.

Sexual health

POI can have an impact on sexual intercourse and how you feel about having sex. These changes can be difficult to deal with especially if you are just starting to explore this area of your life. Here are some of the ways that you may be affected physically and emotionally:

Body image

During menopause your body may change due to altering levels of hormones which can change the way your skin or hair looks. Menopause can change your weight and can give you joint or muscle aches. This may make you feel unattractive and not like yourself which can impact on your interest in having sex.

Low libido

Low libido can describe the feeling of not wanting to have sex or a loss of interest in sex. A loss of interest in sex may stem from a decline in certain hormones or from the changes going on in your body such as vaginal dryness,

pain, hot flushes, etc. These issues can make you feel like you do not have an interest in sex, that you are unattractive and so you do not want to engage in any sexual activities.

Vaginal dryness

Vaginal dryness may cause discomfort during sex which can make you feel like you cannot have or enjoy sex or masturbation. There are moisturisers and lubricants available to help ease dryness. Please make sure that this is one you can use with latex/rubber as some of these may break down condoms, diaphragms or dental dams. You may need to use additional types of contraceptive for protection against sexually transmitted infections or a small risk of pregnancy when using lube. Additionally, some lubricants or moisturisers are hormone based which you may not be able to use if you have a hormone receptive cancer. If you are unsure about this, please ask for more advice from your treating team as they may have some recommendations for these.

Please discuss any issues with your treating team rather than a general sexual health service as they will have the best knowledge of what you can access after the treatment you have received.

Vaginal pain

Due to low levels of oestrogen your vagina may expand less during sex and may feel dry or itchy. This can make sex feel painful or uncomfortable. You may also experience vaginal atrophy which can make the vagina smaller/thinner/ drier. This can cause pain during sex or masturbation.

Any of these sexual health issues can affect how you feel about yourself and how you feel about having sex. This may have an impact on your relationship or future relationships. Although it may feel difficult it is important that you talk

about any changes that you are going through with your treating team. It may be easier to discuss these first with your partner who can support you and provide other ways to explore intimacy with you. Additionally, this may be a time for you to explore what you do and don't like sexually either individually or with a partner.

Tell your treating team if you experience pain, discomfort or issues with sex or masturbation, there are things that can help:

- Dilators these will help to stretch the vaginal walls, and help keep the vaginal tissues soft and more mobile
- Using vibrators this help the blood flow in the vagina due to the vibration on the vaginal walls, helping the above and may even increase natural lubrication
- Using lubrication this will help to slide, and prevent any sticking to the walls of the vagina

It is important to remember that lots of people go through these issues. Your treating team will be used to discussing them and are there to offer you any help and support. Psychosexual counsellors can also be very helpful if you and your partner would like some extra support. You can discuss this with your treating team.

Peer support

Sometimes friends and family might not be able to understand everything that you are going through, and this may make you feel like you are on your own. Talking to someone who is going or has gone through something similar to you can really help. It can help you to regain a sense of normality and make you feel a little bit more like yourself again. Having someone you can talk to who understands first-hand what you are going through can help make you feel less on your own.

Places offering advice and support

Cancer Research

www.cancerresearchuk.org

Daisy Network

www.daisynetwork.org

Health Talk

www.healthtalk.org/menopause/early-premature-menopause

International Menopause Society

www.imsociety.org

Macmillan

www.macmillan.org.uk

Megs Menopause

www.megsmenopause.com

Menopause Matters

www.menopausematters.co.uk

Menopause Support

www.menopausesupport.co.uk

NHS

www.nhs.uk/conditions/early-menopause

Trekstock

www.trekstock.com

MythBusters

Here are some common myths around POI and the actual facts.

Myth #1: I cannot use Hormone Replacement Treatment (HRT) because I have had cancer

Fact: This all depends on the type of cancer that you have had. If you have had a hormone-related cancer then your doctor may advise against the use of HRT. For hormone-related cancers there may other alternative treatment options available but you would need to discuss this with your treating team. It may be worth speaking to your treating team about a referral to an endocrinologist/gynaecologist or a menopause specialist who can support with advice around hormones.

Myth #2: I feel like I am on my own in all of this

Fact: You are not alone. Although the number is small there are still other young women going through something similar. Young women who are likely to go through menopause as a result of their diagnosis or treatment for cancer should have access to a menopause specialist. Although this support may be available it may not be initially offered. Please ask your treating team for a referral to a menopause specialist or a team who can offer further support.

Myth #3: Weight gain is inevitable in menopause

Fact: Unwanted weight gain is common in menopause but not inevitable. As you enter menopause, oestrogen levels drop and may create a hormonal imbalance. Your body reacts by trying to protect itself by actually storing fat, especially around the waist, hips and thighs. Since fat tissue also acts as a source of oestrogen, your body holds on to it even more as your oestrogen levels continue to fluctuate.

With these changes taking place in your body, you'll find a healthy weight by changing your diet and establishing exercise habits. One of the most important things you can do is eat! We've seen again and again how good nutrition helps women balance their hormones and find a way to overcome menopause weight gain.

A dietitian can offer support with a healthy diet and a way to manage your weight. Treating teams may be able to support with this or offer a referral to the relevant team to help you.

Myth #4: Menopause gives you weak bones

Fact: Loss of oestrogen will cause a reduction in bone density over time. Treatment with oestrogen containing HRT can return bone density to original levels. There are also other healthy lifestyle choices that can help support bone health even if you are unable to take HRT. These include maintaining a healthy diet and weight, taking exercise especially weight training and weight bearing exercise, with sufficient calcium intake (700-1000 mg per day) and vitamin D levels (either through sunlight or supplementation). If your bone strength does drop, this can be detected with a DXA scan and there are other treatments available to prevent fractures, if required.

Myth #5: The first sign of menopause is hot flushes.

Fact: Even though menopause and hot flushes are commonly associated, your first sign of menopause could be any of the following:

- Anxiety
- Fatigue
- Weight gain
- Low libido

- Hair loss
- Food cravings
- Fuzzy thinking/forgetfulness
- Irritability, mood swings, depression and/or anxiety
- Irregular periods
- Adult acne
- Sleep difficulties
- Vaginal dryness
- Joint discomfort/stiffness
- Digestive discomfort
- Feeling overwhelmed
- PMS-like symptoms, including stronger cramps, bloating, breast tenderness or headaches

It's also important to remember that there's no set pattern for symptoms. You may experience one or many, and each symptom can range dramatically in severity and frequency. Plus, with such a wide variety of symptoms, it's no wonder that women may not immediately connect them to menopausal hormonal imbalance.

It is not a checklist it can be one, two or all these. Some people may have no symptoms at all. A blood test can determine whether you are menopausal. Don't just wait until you have symptoms if you are high risk. You can be monitored for this through blood tests.

Myth #6: After menopause, your body doesn't produce hormones.

Fact: No matter how far beyond menopause you may be, you still have hormones! Your sex hormones oestrogen, testosterone, and progesterone decline once you go through menopause, but you still need them and make them, just in

lower amounts, for example from your adrenal glands and fat cells.

These hormone levels can vary depending on your age and treatment you may have had (surgery, bone marrow transplant (BMT), chemotherapy and radiotherapy).

Myth #7: Menopause only causes physical symptoms.

Fact: Menopause symptoms can be related to thinking and emotions. Sudden shifts in our hormones can lead to changes in mood, memory and concentration.

Oestrogen and progesterone are key hormones that have an impact on our neurotransmitters. Neurotransmitters are the molecules used by the nervous system to transport messages between neurons (nerve cells), or from neurons to muscles. Neurotransmitters are often referred to as the body's chemical messengers.

For example, oestrogen inhibits the breakdown of serotonin and makes higher levels of serotonin available in the brain which helps to keeping us feeling happy.

Oestrogen also increases acetylcholine which is our neurotransmitter or our body's chemical messenger related to memory. Progesterone has an effect on receptors which plays an important role in behaviour, cognitive and the bodies response to stress and helps us to relax and not be so anxious.

Overall, menopause can be a time of stress influencing your emotions. In fact, perimenopause and menopause are sometimes referred to as the 'flip side of puberty' with similar emotional ups and downs. Your treating team may be able to advise on any services to support your mental health so please ask for help when you need it. Other charities may be able to offer further support around general mental health issues:

Anxiety UK:

www.anxietyuk.org.uk

CALM:

www.thecalmzone.net

CAMHS:

Contact your local link for more advice.

Hub of Hope:

www.hubofhope.co.uk (here you can search for local services available to you).

KOOTH:

www.kooth.com

MIND:

www.mind.org.uk/information-support/for-childrenand-young-people

Papyrus:

www.papyrus-uk.org

Samaritans:

www.samaritans.org

Young Minds:

www.youngminds.org.uk

Myth #8: There's no difference between natural menopause and treatment induced menopause

Fact: Natural menopause and treatment induced menopause are very different.

Surgical menopause can be abrupt. Chemotherapy agents can cause quite sudden onset menopause. Total body irradiation (TBI) and pelvic radiotherapy effects tend to be more gradual.

Even after pelvic radiotherapy women can carry a pregnancy. It slightly depends on the age they had radiotherapy and the dose received by the uterus.

When the uterus is removed but the ovaries are left inside, changes become less predictable and you may not experience POI. However other cancer treatments that you may have alongside surgery may result in you experiencing POI. The truth is that every woman's experience of menopause is different.

Myth #9: The only way to get through menopause is to take hormones

Fact: You always have choices when it comes to your body and your health in menopause. Considering your options is especially important with hormone replacement therapy (HRT) because of the possible risks. If you are talking to your doctor about menopause, we recommend you prepare for your visit and write down questions you may have. You are entitled to a referral to an expert in this area, this can be someone from gynaecology, endocrinology, late effects, etc., services. This should be offered by the team treating you, if not, please ask.

The most thorough and lasting way to manage any symptoms of hormonal imbalance is to listen to your body and adjust your lifestyle, diet and supplemental nutrition to support your body. One of the most effective ways is to use herbal solutions that share important features with our own hormones. These powerful herbs, known as phytocrines can provide relief for specific menopausal symptoms, as well as support your body's own ability to make and use hormones. Phytocrines may not be suitable for everyone so please speak to your treating team before you take anything. They can advise you on whether or not these are safe to take based on your clinical situation. They can also advise on

whether these remedies match your dietary needs as not all remedies may be suitable. For e.g. lactose free, vegan and vegetarian. It is also important to stress that herbal solutions should not be used as a replacement for hormones.

You may be able to use some complementary therapies to help support you through menopause but speak to your treating team first to discuss which of these would be safe for you to engage in.

Contact details

If you have any questions regarding premature ovarian insufficiency and the information in this booklet contact:

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Notes		



Please note:

Mobile phones can interfere with the treatment equipment. Please look out for signs letting you know if it is safe to use your mobile phone. If you do have one with you, you may need to turn it off.

If you need information in a different format, such as easy read, large print, BSL, braille, email, SMS text or other communication support, please tell your ward or clinic nurse.

The Christie is committed to producing high quality, evidence based information for patients. Our patient information adheres to the principles and quality statements of the Information Standard.

If you would like to have details about the sources used please contact the-christie.patient.information@nhs.net

Contact The Christie Hotline for urgent support and specialist advice

The Christie Hotline: 0161 446 3658

Open 24 hours a day, 7 days a week

Visit the Cancer Information Centre

The Christie at Withington **0161 446 8100**The Christie at Oldham **0161 918 7745**The Christie at Salford **0161 918 7804**The Christie at Macclesfield **0161 956 1704**

Open Monday to Friday, 10am – 4pm.

Opening times can vary, please ring to check before making a special journey.

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