



The Leeds
Teaching Hospitals
NHS Trust

Premature Ovarian Insufficiency

Information for patients



Leeds Centre for
Women's Health

This leaflet is for women who have recently been diagnosed with Premature Ovarian Insufficiency (POI).

You can find further sources of information on page 15 and at: www.leedsfertilityclinic.co.uk

How to contact us

Please see page 19 for contact details.

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What is Premature Ovarian Insufficiency (POI)?

A normal menopause is defined as when a woman experiences no menstrual period for 12 months with no other medical explanation. The ovaries stop releasing eggs and the monthly bleed does not occur. It is usually accompanied by classical signs such as hot flushes and mood changes as hormone levels change, particularly oestrogen. The average age that this takes place in the UK is 51 years.

A menopause occurring under 45 years is considered early and a menopause under 40 is premature. Premature menopause is now more commonly known as Premature Ovarian Insufficiency (POI).

How common is POI?

POI is more common than you may expect, affecting approximately 1 in 10,000 women before the age of 20 years, 1 in 1000 before the age of 30 and 1 in 100 before the age of 40.

However, identifying of the condition can be delayed or missed as many women may not present to their doctors or their symptoms are put down to other causes e.g. stress.

What are the symptoms of POI?

The most common symptom experienced is the absence of your monthly menstrual period or having infrequent menstrual periods. However, you may also experience any of the following symptoms:

Physical	Psychological
<ul style="list-style-type: none"> • Hot flushes • Night sweats • Heat intolerance • Palpitations (awareness of heart beat) • Infertility • Changes to skin and hair (dryness, thinning) • Headaches • Breast tenderness • Fat redistribution • Needing to pass urine more often and with more urgency • Pain passing urine • Urinary tract infections/ cystitis 	<ul style="list-style-type: none"> • Mood changes and irritability • Lethargy • Difficulty concentrating • Anxiety/ panic attacks • Depression • Sleep disturbance/ insomnia • Fatigue • Lowered self-esteem
	Sexual
	<ul style="list-style-type: none"> • Reduced sex drive • Vaginal dryness • Pain during sexual intercourse (Dyspareunia)

What causes POI?

In most cases of POI, no specific cause is found. This can often be upsetting and frustrating for the women affected. However, POI can also be attributed to several medical causes such as:

- Genetic reasons e.g. Turners syndrome.
- Autoimmune conditions (when the body develops an intolerance to its own cells such as the ovary).
- Surgical removal of the ovaries.
- Radiotherapy and / or chemotherapy.

Why does POI matter?

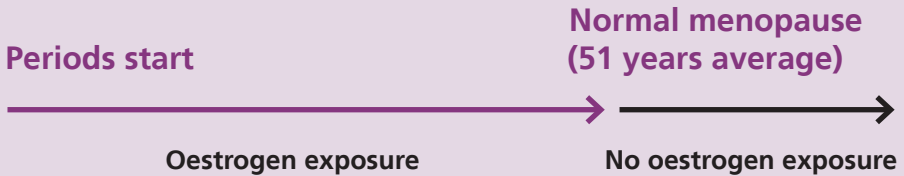
What is oestrogen and why is it important?

Oestrogen is the main hormone that is secreted by the ovaries, along with progesterone and small amounts of testosterone. Oestrogen is important for fertility and egg production, and with progesterone, it helps to prepare the womb for pregnancy. It also plays an important role in keeping bones strong and the heart and blood vessels healthy.

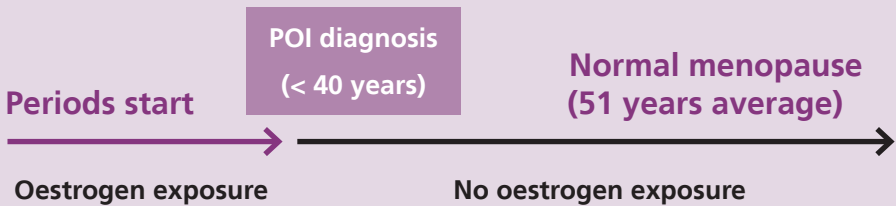
During the perimenopause (the years before and after the last period) oestrogen levels begin to decline to a much lower level. In POI this decline happens earlier so the young woman experiences a longer period of time with oestrogen deficiency. This can lead to the unpleasant symptoms listed above and some long-term health issues outlined on the next page.

Variation of lifetime exposure to oestrogen

Women with menopause after 45 years



Women with premature menopause (POI)



Are there any long term health complications?

Oestrogen deficiency can lead to softening and weakening of the bones which can be measured in a special bone density scan. This can progress into osteoporosis (brittle bones) which can break easily.

A low level of oestrogen for a long time is linked to heart disease, including heart attacks and strokes. It is thought that dementia may be more common too.

How can I protect myself against these complications?

As these complications are caused by a lack of oestrogen, it is important to replace this hormone early in POI. The aim is to give you back the normal oestrogen you should have been making naturally, for as long as you should have been making it (i.e. up to age 51 years).

Hormone replacement therapy (HRT) not only reduces the risk of long-term complications, but also relieves other menopausal symptoms such as hot flushes.

Hormone Replacement Therapy (HRT)

Hormone replacement therapy (HRT) has been proven to be effective, for reducing symptoms like hot flushes and night sweats experienced in POI. HRT is a treatment that gives back the hormones you are missing. This treatment is recommended until at least the average age of menopause, which is 51 years in the UK.

Oestrogen is given with progestogen (progesterone-like hormone) when your womb is still present. Oestrogen is not given alone because this increases the risk of abnormal changes in the womb lining which can become cancerous. Progestogen effectively protects the womb lining from this side-effect.

Types of HRT available

Womb	Present		Absent (hysterectomy) or Mirena coil in place
Pattern of hormones	Cyclical Oestrogen alone for 2 weeks followed by oestrogen and progesterone for 10 -14 days	Continuous Oestrogen and progesterone	Continuous Oestrogen only
Available forms	<p>Tablets: By mouth daily</p> <p>Patches: To stick on the skin (weekly / twice weekly)</p> <p>Gel: To rub in daily</p>		
Bleeding pattern	Monthly	No bleeding (Occasional spotting)	No bleeding (Occasional spotting may occur with Mirena)
Best for	Women with ambitions to become pregnant one day with a donated egg	Post-menopausal women (over 50 years old) who have not had a period for more than 1 year	After a hysterectomy or for women with a Mirena already in who don't want to take two hormones in other forms

Is HRT safe for me?

In recent years, there has been a lot of publicity about the safety of HRT. This has been exaggerated by bad press of studies claiming to have found a link between HRT and an increased risk of breast cancer and heart disease. This has led to women worrying about the safety of HRT. However, these studies **do not apply to women with POI** as they involved women who were much older.

Concerns	The Facts
Does HRT increase my chance of getting breast cancer?	No, your risk of breast cancer is no different to a pre-menopausal woman of the same age if you take HRT. The risk only increases slightly after the age of normal menopause (51 years old) if you choose to continue taking HRT.
Will I have an increased risk of cardiovascular problems?	Again there is no increased risk to a woman under 51 years taking HRT. Studies which suggested this were carried out on women over 51 years and some of the original research has now been deemed inaccurate.
Deep Vein Thrombosis (DVT) (blood clot in the leg veins)	There is a slightly increased risk (as with the contraceptive pill) compared to women not taking hormones. The risk of blood clots with patches / gels at a standard dose is not increased compared with women not using them.
Endometrial cancer (cancer of the womb lining)	Women with a womb should take combined HRT (progestogen and oestrogen) to minimise the risk.

What other treatment options are available?

Other treatments can help to relieve symptoms and improve wellbeing, such as:

- The use of vaginal oestrogen works well for vaginal and bladder symptoms. It is available in creams, tablets and rings.
- Wiping with a cold flannel or having a shower when experiencing hot flushes.
- Various herbal remedies (ALWAYS consult your doctor before commencing these).
- Counselling and support groups.
- Psychosexual advice and support e.g. using lubricating gel / cream.

None of these are substitutes for HRT and they will not protect you against the long term health implications discussed above.

What lifestyle changes should I make?

- **Stop smoking** - smoking reduces the effectiveness of HRT and is a risk factor for cardiovascular disease and osteoporosis.
- **Decrease alcohol intake** - excess alcohol can further reduce bone strength leading to osteoporosis. It also increases your risk of falling which could cause bone fractures.
- **Regular exercise** - aerobic exercise helps to reduce cardiovascular risks whilst weight-bearing exercise protects against osteoporosis.
- **Eating a balanced diet** - this provides important sources of calcium and other essential vitamins and minerals. Dietary supplements such as calcium and vitamin D may be recommended.

Can I still have children?

A very distressing consequence of premature ovarian insufficiency is infertility. This does not necessarily mean you will not be able to have children; a small number of women do get pregnant naturally after POI has been identified. The majority of women will, however, be unable to conceive naturally which can lead to feelings of inadequacy or failure. You may be offered, and you can request a referral to see a fertility specialist to talk about your options. Counselling support with specialised fertility counsellors is available, when you feel you might want to talk about this side of your life.

Despite this there are several options available for women who cannot conceive naturally.

- In vitro fertilisation (IVF) - as the ovaries are no longer functioning efficiently it is necessary to use an egg from another woman (donor egg) to fertilise with your partner's sperm, in order for you to carry the pregnancy and birth your baby. This may not suit every woman but it can be very successful (about half of the women who try will have a baby but it may take more than one treatment attempt). There are lots of things to think about with this type of treatment. Leeds Fertility will provide lots of help and support. More information can be found here:

www.leedsfertilityclinic.co.uk

<http://flipbooks.leedsth.nhs.uk/LN004348/>

- Adoption and fostering - this can be a long process but can be extremely rewarding.

- Positively childless - some women choose not to have children. This should be seen as a positive choice (see story below).

Jean's Story - Jean was diagnosed with POI in her 30's

“Positively Childless to me means total control of my life. I value freedom and independence and want to accomplish/experience things that would be difficult to do if I were a parent. Not having children is liberating, I am happy and my life is full and exciting.”

Additional resources on these topics can be found at the back of this booklet.

How do I cope with this diagnosis?

Being diagnosed with POI can be an extremely distressing time for a woman. It is normal to feel low and stressed when coming to terms with the diagnosis. It is important to realise that you are not alone and there are many other women going through this. It may be helpful to talk to someone about this or to research the condition further.

Several websites and support groups are available and some are listed at the end of this booklet.

What about contraception?

In POI, some women's ovaries go through waves of activity. They can have a few periods and then a gap. This pattern can be repeated. Having a period can be a sign that an ovulation has happened. HRT is not contraceptive so if you want to avoid an unplanned pregnancy you must take precautions. The contraceptive pill can be used as a form of HRT with the same protective benefits of oestrogen, if needed. Other methods of contraception maybe discussed with your GP.

Are there any other hormones that are important in POI?

Testosterone is also produced by the ovaries and levels can fall significantly if both ovaries have been removed. If this occurs, symptoms such as fatigue, low sex drive, low mood and headaches may be experienced. Testosterone replacement can help to relieve these symptoms and can be discussed with your health practitioner.

Useful resources

AdoptionUK

- www.adoptionuk.org
For every adoptive family.

Brilliant Beginnings

- www.brilliantbeginnings.co.uk
Creating UK families through surrogacy.

British Fertility Society

- www.britishfertilitysociety.org.uk
The UK professional society promoting high quality practice and research.

British Infertility Counselling Association

- www.bica.net
The professional association of infertility counsellors in the UK.

COTS

- www.surrogacy.org.uk
Information about surrogacy in the UK.

First4Adoption

- www.first4adoption.org.uk

National information service with local search tool.

GOV.UK Child adoption

- www.gov.uk/child-adoption

Information about adoption in the UK.

Infertility Network UK

- www.infertilitynetworkuk.com

The UK's leading infertility support network offering extensive information and support through treatment. They provide advice regarding funding and a variety of factsheets.

Leeds Fertility

- www.leedsfertilityclinic.co.uk

The local fertility clinic provides expert advice and a comprehensive service to assist conception.

Menopause Matters

- www.menopausematters.co.uk

This is an award winning, independent website providing up-to-date, accurate information about the menopause, menopausal symptoms and treatment options.

One Adoption

- www.oneadoption.co.uk

A regional adoption agency made up of local authority adoption services from West Yorkshire, North Yorkshire, The Humber and North East Lincolnshire.

PAC-UK

- www.pac-uk.org

Independent agency providing specialist therapy, advice, support, counselling and training for all affected by adoption and permanency.

Royal Osteoporosis Society

- <https://theros.org.uk>

UK-wide organisation dedicated to finding a cure for osteoporosis and improving the lives of everyone affected by it.

Surrogacy UK

- www.surrogacyuk.org

A one stop shop for all information about surrogacy in the UK.

TACT Fostering and Adoption

- www.tactcare.org.uk

Fostering and adoption charity.

The Daisy Network

- www.daisynetwork.org.uk

This charity provides support and information for women who are facing premature ovarian insufficiency (premature menopause) and its consequences.

Women's Health Concern (WHC)

- www.womens-health-concern.org

Is the patient arm of the British Menopause Society (BMS) and provides advice, reassurance and reliable information on the latest research for women of all ages about their gynaecological and sexual health, wellbeing and lifestyle concerns.

Contact us

Leeds Fertility

By post

- Leeds Fertility, Leeds Teaching Hospitals NHS Trust, Seacroft Hospital, York Road, Leeds, LS14 6UH

By Email

Egg donation coordinator (Nurse Specialist)

- leedsth-tr.Eggdonors@nhs.net

Online

- Web: www.leedsfertilityclinic.co.uk

By telephone

Mon-Fri 08.00-17.00

- For all NHS appointments: 0113 206 3100
- For clinical queries: 0113 206 3102

Sat-Sun 08.00-12.00

- Clinical queries only: 0113 206 3102

Menopause@Meanwood

By post

- **Meanwood Health Centre, 548 Meanwood Road,
Leeds, LS6 4JN**

By Email

- **menopause.meanwood@nhs.net**

By telephone

Mon-Fri 08.00-16.00

- **For all queries: 0113 295 1753**

Questions / Notes

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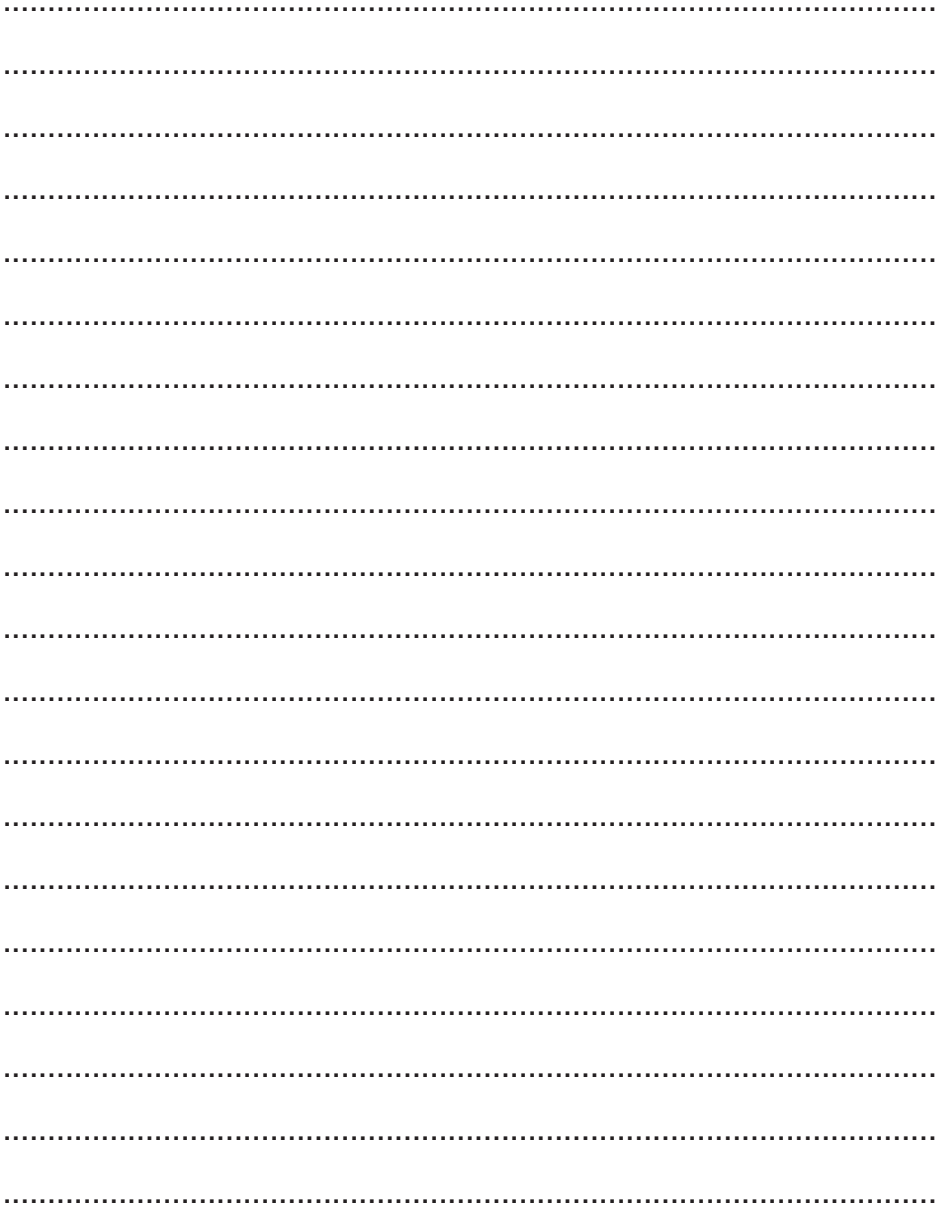
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