

Premature ovarian insufficiency

Information for patients

What is premature ovarian insufficiency?

Premature ovarian insufficiency (POI) is where the ovary runs out of eggs much earlier than it should. There can be a premature menopause when your periods stop much earlier than normal. Sometimes, before a premature menopause, you may have irregular periods and longer or shorter gaps between periods. The average age of the menopause is 51 years old, but those with POI may go through the menopause any time before the age of 40. It affects approximately 1% of those under 40 years old.

What are the signs and symptoms of POI?

With POI, the ovaries stop releasing eggs regularly much earlier than usual. This initially leads to irregular periods that are less frequent, although sometimes the gap between periods can be shorter. Eventually your periods will stop altogether.

The ovaries will also stop producing hormones such as oestrogen, progesterone and testosterone, which can lead to the following symptoms:

- Hot flushes
- Night sweats and sleep disturbance
- Mood changes
- Vaginal dryness
- Low libido
- Fatigue
- Difficulty concentrating
- Infertility.

What causes POI?

There are many possible causes of POI. The majority of patients will have unexplained, or "idiopathic" POI which means that no underlying cause can be identified.

Other causes include autoimmune disease (where your body's immune system damages your own body, which can include damage to the ovaries), genetic differences (for example, Turner's Syndrome and Fragile X Syndrome), or, much more rarely, infection.

POI can also be "iatrogenic" – this means it has been caused by medical treatment you have received, such as chemotherapy, radiotherapy or surgery (where both ovaries are removed).

How is POI diagnosed?

If you are under 40 years old and have no periods, infrequent periods, or an altered pattern of periods over several months, two blood tests (performed 4 to 6 weeks apart) can be performed to help diagnose POI. If you have POI, these blood tests will show high levels of follicle stimulating hormone (FSH) while the oestrogen is low or borderline low on both occasions.

To try and find a possible cause, further blood tests can be performed which look at your chromosomes (for genetic causes) and specific antibodies (for autoimmune causes). If these tests are negative, then it is called idiopathic POI. Your doctor may also arrange a bone scan to assess your bone density.

How can POI affect me?

As well as the symptoms mentioned above, POI can affect other aspects of your health. Low oestrogen levels lead to:

- Reduced bone mineral density, which can result in osteoporosis and an increased risk of fractures
- Increased risk of heart disease
- Effects on memory.

As the ovaries also stop releasing eggs regularly, it can mean the chances of getting pregnant naturally are much lower.

What treatments are available?

Unfortunately, there is no cure for POI. That is because all the eggs in the ovary are made before you are born and after that no new eggs are made. However, there are treatments available to improve symptoms and reduce the long-term effects on your health.

Hormone replacement therapy (HRT)

It is important to replace the hormones to a level similar to those found in women of a similar age who don't have POI. HRT not only helps menopausal symptoms, but it also provides bone protection and may prevent heart disease caused by low oestrogen levels. It is therefore recommended that women with POI start HRT soon after diagnosis and continue it until at least the age of natural menopause (51 years old) unless a health professional has advised you otherwise. Studies have shown that using HRT for POI does not increase the risk of breast cancer in women under 50 years of age. There are some health conditions where HRT would not be advised. Your doctor will be able to advise you further if this is the case.

Oestrogen can be given in the form of tablets, patches or gel. If you have a uterus, you will also need progesterone replacement. This can be given in the form of a tablet or an intrauterine system (often referred to as a coil). HRT is not a contraceptive and therefore if you have had a period within the last 2 years and don't want to become pregnant, you can use the combined oral contraceptive pill instead of HRT. If you have certain underlying conditions your doctor may suggest using specific types of HRT.

Small doses of testosterone, given in gel form, can be useful for lack of libido. This is generally prescribed by menopause specialists as there is no approved testosterone preparation for this.

Vaginal oestrogen replacement

If vaginal dryness is a problem for you, often this will be improved by the HRT. Sometimes this is insufficient, and then oestrogen can be administered directly into the vagina, either by cream, pessaries or a special silicone ring that stays in the vagina for 3 months at a time (called an Estring[®]). These can be used in addition to HRT.

Non-hormonal lubricants are also available, which can help if vaginal dryness is causing sex to be uncomfortable.

Healthy lifestyle

Maintaining a healthy lifestyle (eating a healthy diet with adequate calcium and vitamin D, limiting alcohol, stopping smoking, having a healthy weight and exercising) is important to reduce the effects on your bones, heart and brain.

Complementary therapies

There is not enough evidence to say that complementary therapies are safe and effective in improving the symptoms of POI.

Is it possible to have a family?

It is possible to get pregnant naturally if you have POI. However, the chances are much lower than for someone else your age. Unfortunately, there are no available treatments to increase the number of eggs you have and in vitro fertilisation (IVF) is unlikely to be successful using your own eggs. We also don't yet have any ability to store any remaining eggs within the ovary to preserve fertility in POI.

If you haven't been unable to conceive naturally, it is possible to get pregnant using an egg donor. If you have a uterus, any embryos created by IVF from the donated eggs could be implanted back into you. This means you could carry the pregnancy and deliver your baby.

Finally, adoption is another option if you would like to have a family.

What follow up can I expect?

If you are on HRT, you should be seen annually by your GP or a specialist doctor. This should include a blood pressure check.

Your doctor may request a further bone scan (called a DEXA scan) every 3-5 years if your bone density is low, to check for osteoporosis.

If you are experiencing problems requiring specialist advice, then your GP may refer you to a menopause specialist.

Where can I get more support?

Daisy Network (https://www.daisynetwork.org) – a national charity supporting those experiencing POI

Fertility Network UK (<u>http://fertilitynetworkuk.org</u>) – a national charity supporting those experiencing infertility. Their website has information specific to those diagnosed with POI.

Contact details

Edinburgh Fertility and Reproductive Endocrine Centre (EFREC) 0131 242 2460 (In office hours)