

Premature Ovarian Insufficiency or POI

Patient Information Series – What you should know, what you should ask.

What is Premature Ovarian Insufficiency (POI)?

POI occurs when the ovaries stop making a mature egg each month, leading to irregular menstrual periods and eventually, no periods at all. Patients with POI enter menopause before the age of 40, compared to the average age of menopause of 51. Your doctor will order a blood test called follicle-stimulating hormone (FSH) which will be elevated, over 25 IU/mL. This is a sign that the pituitary gland in your brain is working well to send a strong signal to the ovaries, but the ovaries are no longer responding. Patients often experience symptoms including hot flashes, sleep disturbances, mood changes, and sexual dysfunction.

How common is POI and how does it happen?

POI is relatively common, affecting about 1 in 100 patients. Some studies are now suggesting the incidence is even higher as the diagnosis is often delayed (patients may see more than 1 specialist before they receive a diagnosis). Testing will be done to determine the cause of the POI. Sometimes no obvious cause is found.

The most common reasons are genetic and autoimmune (the body has an immune response against its own cells). However, it can also be caused by a medical treatment such as chemotherapy or radiation for cancer, or surgical removal of the ovaries. Patients with a family history of POI are at a higher risk. Rare metabolic conditions can also cause POI as can some lifestyle choices, such as smoking. The chemicals in cigarettes can be toxic to the ovary.

How are chromosomes and genetics relevant to POI?

Chromosomes are where most of our genetic information is kept. We usually have 46 of them matched in pairs: 23 come from one parent and the other 23 come from the other parent. In Turner Syndrome, girls are born with 45 chromosomes because one X chromosome is missing.

Another genetic cause is Fragile X pre-mutation, where there are more amino acid repeats than normal (55-200) in the DNA. This can cause POI as well as certain movement disorders, known as ataxia.

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Should I have more tests?

Many patients will be advised to have more tests to know more about the condition and the underlying cause. After a thorough history of risk factors and physical examination, additional tests your doctor may recommend include:

- Hormone testing to look for other causes of irregular periods or no periods (FSH, estradiol, thyroid testing, and looking for elevated prolactin hormone which can stop ovulation from occurring)
- Genetic testing (Karyotype for Turner Syndrome and FMR1 premutation testing for Fragile X Syndrome)
- Autoimmune testing (antibodies against the thyroid gland and adrenal gland)
- Bone density testing (called a dual-energy X-ray absorptiometry scan or DEXA) to assess bone health due to early menopause and the risk of low bone density or osteoporosis
- General medical health testing (testing for diabetes, cholesterol, and other conditions which are important to find and optimise in patients with a POI diagnosis)

What does it mean for me long term and is there treatment?

Patients with POI are at long-term risk of early heart disease and osteoporosis as well as genitourinary syndrome of menopause (prone to bladder infections and painful intercourse). The diagnosis can be difficult for patients, and they may require psychological or spiritual counseling as they navigate a treatment pathway tailored to their needs.

There is no cure for POI but the symptoms can be treated by replacing the hormones (estrogen and progesterone) that are not being made by the ovary anymore. This is called hormone replacement therapy or HRT. We recommend you speak to your doctor about the best form of HRT for you (which may include a hormonal birth control method, patches, or pills). Some patients cannot take estrogen due to medical reasons and other options are available in this situation. Patients without a uterus do not usually require progesterone replacement.

What does it mean for my future fertility?

Some patients are identified to be at risk for POI in the future. For example, receiving a cancer diagnosis that requires chemotherapy or requiring surgical removal of the ovaries. Before this treatment, there is sometimes the option to freeze your eggs (fertility preservation), to have the opportunity to have genetic children in the future with fertility treatments like invitro fertilization. Many patients will not receive a diagnosis of POI until their ovaries are already not working. In this situation, we recommend speaking to a fertility specialist about using an egg donor. Using an embryo donor or adoption are other options.

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In many situations, patients with POI can still carry a pregnancy, and we recommend you speak to your doctor to see if this is safe for you. There are some conditions that cause POI, such as Turner Syndrome, that are associated with higher risks in pregnancy and will require care from a multidisciplinary team.

Can POI be prevented?

POI is generally not preventable. However, a healthy lifestyle including optimising overall health and avoiding cigarette smoking can help decrease your risk.

What other questions should I ask?

- Are my irregular periods, or lack of periods a sign of POI or something else?
- What does POI look like on ultrasound?
- What other testing do I need to complete?
- What are my options for future fertility?
- Are my future children at risk?
- Can I be referred to a specialist with expertise in investigating and treating POI?
- What treatments are available?

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