

Premature ovarian Insufficiency (POI)

This information sheet has been given to you to help answer some of the questions you may have about premature ovarian insufficiency (POI). If you have any further questions, please speak to a doctor or nurse in the clinic.

What is premature ovarian insufficiency?

Premature ovarian insufficiency is a loss of ovarian function before the age of 40. Other terms sometimes used to describe the condition are 'primary ovarian failure' and 'premature menopause'. It is suggested that a menopause is early if it occurs between 40-45 years old. This can be natural or induced by surgery, where your ovaries are removed, or medication that stops the ovaries working.

What do the ovaries normally do?

The ovaries produce hormones called oestrogen and progesterone in response to other hormones (follicle stimulating hormone (FSH) and luteinising hormone (LH) which are made in a part of the brain called the pituitary gland. All these hormones interact as part of the monthly menstrual cycle which results in the development of an egg in one of the ovaries.

In premature ovarian insufficiency, the ovaries stop producing normal levels of oestrogen and may not produce eggs.

What are the signs and symptoms?

Periods may become infrequent or stop. There may be other symptoms such as:

- hot flushes
- night sweats
- palpitations
- decreased energy levels
- lack of concentration
- poor sleep
- lack of interest in sex
- vaginal dryness
- painful intercourse.
- mood changes
- longer term risks of increased cardiovascular disease
- longer term risk of thinning bones (osteoporosis).

How common is premature ovarian insufficiency?

It affects about one in 100 women before the age of 40 and five in 100 women before the age of 45.

Age	Number of women affected
Under 20	1 in 10 000
Under 30	1 in 1000
Under 40	1 in 100
41-45	5 in 100

Why does premature ovarian insufficiency happen?

There are many different causes for POI and most of the time the cause is unknown and it can run in families.

Some of the causes are:

- Surgery - removal of your ovaries means there will be no oestrogen in your body and you will experience the symptoms of the menopause.
- Cancer treatments - some chemotherapy and radiotherapy can stop your ovaries from working. This can be temporary in some women. It is important to talk about fertility before you have these treatments.
- Auto immune diseases - for some women the immune system which should protect the body attacks it. Examples of this can be diabetes, thyroid problems.
- Genetic conditions - It can occasionally be due to chromosome or gene problems such as Turners syndrome.
- Infections - very rarely infections such as mumps and TB have been associated with POI.
- No known cause - This is known as idiopathic.

How is POI diagnosed?

Women who have had their ovaries removed do not need a test to diagnose POI.

Women with POI usually have raised FSH levels and low levels of oestradiol (oestrogen). This is because in POI the ovaries do not produce normal levels of oestradiol so the pituitary reacts by making more FSH to try to stimulate the ovaries to produce oestradiol. Your FSH and oestradiol levels will be measured by a blood test.

If you are having periods, it is very important that the blood test is done at the correct time in the cycle (the **beginning – day 2 to 4 of your period**) because FSH goes up later on in a normal cycle. If you are not having periods, you can have the test on any day. It is also important that the blood test is performed twice, at least four weeks apart, to confirm the diagnosis.

Do I need any more tests?

You will also be offered a blood test to check for diabetes and thyroid problems. This is because premature ovarian insufficiency failure is sometimes associated with these conditions. If you are under 35 you may be offered a blood test to check your chromosomes. Chromosomes are found in every cell in the body and contain genetic information. Very rarely, premature ovarian insufficiency can be caused by a problem with the chromosomes.

All women will be offered a painless x-ray bone scan (known as a DXA), which checks for bone density. This is done because a low level of oestrogen can cause osteoporosis (thinning of the bones).

Is idiopathic (unknown) POI the same as the normal menopause?

No, it is not the same as the menopause which occurs at an average age of 51 in the UK. The normal menopause occurs when there are no more follicles (developing eggs) in the ovaries and it is irreversible.

In POI, the function of the ovaries can return intermittently and some women may even start to have periods or become pregnant many years later, although this is rare.

What effect will premature ovarian insufficiency have on my long-term health?

The low oestrogen level in POI can cause osteoporosis, which can lead to fractures. It probably also causes an increase in cardiovascular risk (the risk of having a heart attack or stroke), which is also influenced by many other things, for example smoking, diet, exercise and weight.

POI can be a very difficult diagnosis to come to terms with and many women have feelings of anxiety and low mood following the diagnosis. It is important to seek help if you feel like this or feel that you are unable to cope. Some women find that a support group and talking to other women with POI is helpful (see websites below); others find talking to friends or family or having counselling sessions can help.

What treatments are available?

There have not been any studies evaluating the best treatment for POI. Most specialists recommend that women with POI take oestrogen replacement because the oestrogen level is very low and this can cause bone thinning and an increase in cardiovascular risk, as well as causing many of the symptoms mentioned above.

Oestrogen replacement can be given as HRT (hormone replacement therapy) or the combined oral contraceptive pill. There are many different types of HRT and pills and the doctors and nurses in clinic will be able to give you further information. It is up to you to decide whether you would like to take oestrogen replacement and if so, which pill or HRT you would like to take.

It is important to remember that if your first treatment does not suit you there are likely to be alternatives.

If you have had treatment for a gynaecological cancer, your medical team or clinical nurse specialist will be able to arrange for you to come to a specific clinic to be assessed for possible hormone replacement or treatment for POI.

Will I be able to get pregnant?

Unlike women with regular periods, women with POI do not ovulate (release an egg) every month. However, studies have shown that women with idiopathic POI do sometimes ovulate and approximately 5–10% will become pregnant over their lifetime. Unfortunately, there is no way of predicting which group of women this will happen to. You may read about ultrasound scans and blood tests being used to try to predict if there are any eggs left, but these are not proven and are currently only used in research settings.

The combined oral contraceptive pill is not a suitable treatment for you if you want to become pregnant because it prevents ovulation. If you want to see a fertility specialist, ask the doctor or nurse you see in clinic. If you have a diagnosis of early menopause then ovum donation (egg donation) is normally needed for assisted conception. If you do not want to become pregnant, it is important that you continue with contraception, as women with POI can conceive naturally.

Where can I get more information?

The Daisy Network – A patient run support group based in UK
w: www.daisynetwork.org.uk

International Premature Ovarian Failure Association
w: www.pofsupport.org

Human Fertility and Embryology Association – Information about IVF and list of clinics
w: www.hfea.gov.uk

National Gamete Donation Trust – Information about donor eggs
w: www.ngdt.co.uk

British Infertility Counselling Association – List of counsellors
w: www.bica.net

Contact us

If you have any questions or concerns about premature ovarian failure please contact the Gynaecology results line on **020 7188 3023 on Wednesday from 2-4 at other times**, if there is no answer, please leave a message and we will get back to you. Or email GynaecologyResults@gstt.nhs.uk

Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.

t: 020 7188 8748 9am to 5pm, Monday to Friday

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk

t: 020 7188 3514 (complaints) **e:** complaints2@gstt.nhs.uk

Language Support Services

If you need an interpreter or information about your care in a different language or format, please get in touch:

t: 020 7188 8815 **e:** languagesupport@gstt.nhs.uk

NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

t: 111

NHS Choices

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

w: www.nhs.uk

Get involved and have your say: become a member of the Trust

Members of Guy's and St Thomas' NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, and to become a member:

t: 0800 731 0319 **e:** members@gstt.nhs.uk **w:** www.guysandstthomas.nhs.uk/membership

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