

Information for patients

What is polycystic ovary syndrome?

Polycystic ovary syndrome (PCOS) is a condition that can affect your periods, fertility, hormones and aspects of your appearance. It can also affect your long-term health. Estimates of how many women it affects vary widely from 2 to 26 in every 100 women. It is formerly known as the Stein-Leventhal syndrome, you have the condition if you have at least two of the following:

- At least 12 tiny cysts (follicles) develop in your ovaries (polycystic means many cysts)
- The balance of hormones that you make in the ovaries is altered. In particular, your ovaries make more than normal of the male hormone testosterone
- You do not ovulate each month. Some women do not ovulate at all. In PCOS, although the ovaries usually have many follicles, they do not develop fully and so ovulation often does not occur. If you do not ovulate then you may not have a period

It is possible to have ovaries that are polycystic without having the typical symptoms that are in the syndrome. It is also possible to have PCOS without having multiple cysts in the ovary.

What are the symptoms of polycystic ovary syndrome?

Symptoms that occur if you do not ovulate

- **Period problems** occur in about 7 in 10 women with PCOS. You may have irregular or light periods, or no periods at all
- **Fertility problems** – you need to ovulate to become pregnant. You may not ovulate each month. Some women with PCOS do not ovulate at all. PCOS is one of the most common causes of not being able to get pregnant (infertility). For further information see Fertility: Assessment and Treatment for People with Fertility Problems, which is produced by the National Institute for Health and Care Excellence (NICE) and is available at: www.nice.org.uk/guidance/cg156

You may still become pregnant even if you do not have periods. If you do not want to become pregnant, you should seek advice from your GP about contraception.

Symptoms that can occur if you make too much male hormone testosterone

- **Excess hair growth (hirsutism)** occurs in more than half of women with PCOS. It is mainly on the face, lower tummy (abdomen) and chest. In other words, it tends to be male-pattern hair. This does not happen to all women with PCOS
- **Acne** may persist beyond the normal teenage years
- **Thinning of scalp hair** (similar to male pattern baldness) occurs in some cases

Other symptoms:

- **Weight gain** – women with PCOS are more at risk of becoming overweight or obese

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- **Depression** or poor self-esteem may develop as a result of the other symptoms

Symptoms typically begin in the late teens or early 20s. Not all symptoms occur in all women with PCOS. For example, some women with PCOS have some excess hair growth but have normal periods and fertility.

Symptoms can vary from mild to severe. For example, mild unwanted hair is normal, and it can be difficult to say when it becomes abnormal in women with mild PCOS. At the other extreme, women with severe PCOS can have marked hair growth, infertility and obesity. Symptoms may also change over the years. For example, acne may become less of a problem in middle age but hair growth may become more noticeable.

What causes polycystic ovary syndrome?

The exact cause is not totally clear. Several factors probably play a part. These include the following:

Insulin

Women with PCOS have what is called insulin resistance. This means that cells in the body are resistant to the effect of a normal level of insulin. More insulin is then produced to keep the blood sugar normal. This raised level of insulin in the bloodstream is thought to be the main underlying reason why PCOS develops.

Luteinising hormone (LH)

This hormone is made in the pituitary gland, which is located in the base of the brain. It stimulates the ovaries to ovulate and works alongside insulin to promote testosterone production. A high level of LH is found in about 4 in 10 women with PCOS.

Hereditary factors

PCOS is not usually inherited from parents but it may run in some families. There seems to be a hereditary (genetic) factor involved in some cases but this is not yet understood.

Weight

Being overweight or obese is not the underlying cause of PCOS. However, if you are overweight or obese, excess fat can make insulin resistance worse. This may then cause the level of insulin to rise even further. High levels of insulin can contribute to further weight gain producing a 'vicious cycle'. Losing weight, although difficult, can help break this cycle.

How is PCOS diagnosed?

Having polycystic ovaries does not mean you have PCOS.

Women with PCOS often have symptoms that come and go, particularly if their weight goes up and down. This can make it a difficult condition to diagnose, which means it may take a while to get a diagnosis.

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A diagnosis is made when you have any two of the following:

- irregular, infrequent periods or no periods at all
- an increase in facial or body hair and/or blood tests that show higher testosterone levels than normal
- an ultrasound scan that shows polycystic ovaries. When a diagnosis is made, you may be referred to Gynaecologist (a doctor who specialises in caring for a woman's reproductive system) or an endocrinologist (a doctor who specialises in the hormonal system)

What could PCOS mean for my long-term health?

If you have PCOS, you are at greater risk of developing the long-term health problems discussed below.

Insulin resistance and diabetes

One or two in every ten women with PCOS go on to develop diabetes at some point. If the diabetes is untreated, this can cause damage to organs in the body.

If you have PCOS, your risk of developing diabetes is increased further if you:

- are over 40 years of age
- have relatives with diabetes
- developed diabetes during a pregnancy (known as gestational diabetes)
- are obese (a body mass index (BMI) of over 30)

High blood pressure

Women with PCOS tend to have high blood pressure. High blood pressure can lead to heart problems and should be treated.

Cancer

If you have fewer than three periods a year, the lining of the womb (endometrium) can thicken and this may lead to endometrial cancer in a small number of women.

PCOS does not increase your chance of breast or ovarian cancer.

Depression and mood swings

The symptoms of PCOS may affect how you see yourself and how you think others see you. It can lower your self-esteem.

Snoring and daytime drowsiness

PCOS can lead to fatigue or sleepiness during the day. It is also associated with snoring.

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What can I do to reduce long-term health risks?

Have a healthy lifestyle

The main ways to reduce your overall risk of long-term health problems are to:

- eat a healthy balanced diet. This should include fruit and vegetables and whole foods (such as wholemeal bread, whole-grain cereals, brown rice and whole-wheat pasta), lean meat, fish and chicken. You should cut down the amount of sugar, salt and caffeine that you eat and drink. You should not drink more alcohol than is recommended (14 units a week for women)
- eat meals regularly, especially breakfast
- take exercise regularly (30 minutes at least three times a week)

Your GP or practice nurse can provide you with full information on eating a healthy diet and exercise.

You should aim to keep your weight to a level that is normal. BMI is the measurement of weight in relation to height and you should aim to keep your BMI between 19 and 25.

If you are overweight, it would be helpful to lose weight and maintain your weight at this new level. If your BMI is more than 30, discuss ways of losing weight, including weight-reducing drugs, with your GP, practice nurse or pharmacist.

The benefits of losing weight include:

- a lower risk of insulin resistance and developing diabetes
- a lower risk of heart problems
- a lower risk of cancer of the womb
- more regular periods
- an increased chance of becoming pregnant
- a reduction in acne and a decrease in excess hair growth over time
- improved mood and self-esteem

You only have to lose a small amount of weight to make a difference to your symptoms and your health.

Have regular health checks

Once you have a diagnosis of PCOS, you will be monitored to check for any early signs of health problems:

- **Diabetes:** Women with PCOS over the age of 40 should be offered a blood sugar test once a year to check for signs of diabetes

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- **Cancer of the womb:** If you have not had a period for a long time (over 4 months) or have irregular bleeding, it is advisable to see your doctor. You may be offered a referral for further tests that may include an ultrasound scan of your womb (uterus) or treatment to make you have a period if they are very irregular
- **High blood pressure:** Discuss with your doctor how often you should have your blood pressure checked and whether you should have blood tests to check your cholesterol levels
- **Depression and psychological problems:** You can be referred to a counsellor or trained specialist if necessary

What is the treatment for polycystic ovary syndrome?

There is no cure for PCOS. However, symptoms can be treated and your health risks can be reduced, losing weight helps to reduce the high insulin level that occurs in PCOS.

Treating hair growth

Hair growth is due to the increased level of the hormone testosterone.

Unwanted hair can be removed by:

- Shaving
- Waxing
- Hair-removing creams
- Electrolysis
- Laser treatments

These need repeating every now and then, although electrolysis and laser treatments may be more long-lasting (but are expensive and are often not available on the NHS).

There are also some medicines which may be helpful. A cream called eflornithine may be prescribed to rub on affected areas of skin. It can reduce unwanted hair growth, although this effect quickly wears off after stopping treatment.

Medicines taken by mouth can also treat hair growth. They work by reducing the amount of testosterone that you make:

- Anti-testosterone medicine called Dianette®. It is commonly prescribed to regulate periods, help reduce hair growth, reduce acne and provide contraception
- The combined oral contraceptive pill Yasmin® has been shown to help if Dianette® is not suitable
- Other anti-testosterone medicines are sometimes advised by a specialist if the above treatments do not help

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Medicines taken by mouth to treat hair growth take 3-9 months to work fully. You need then to carry on taking them, otherwise hair growth will come back (recur). Removing hair by the methods above (shaving, etc) may be advised whilst waiting for a medicine to work.

Treating acne

The treatments used for acne in women with PCOS are no different to the usual treatments for acne. The combined oral contraceptive pills can help to improve acne.

Treating period problems

Some women who have no periods, or have infrequent periods, options of treatment like taking combined contraceptive pill, or pills that contain progesterone hormone only, this will cause a monthly bleed like a period. Sometimes Mirena coil can be used which releases small amounts of progesterone into the womb, preventing a build-up of the lining, can be used. If none of these methods is suitable, your doctor may advise a regular ultrasound scan of your uterus to detect any problems early.

Fertility issues

Although fertility is often reduced, you still need contraception if you want to be sure of not getting pregnant. The chance of becoming pregnant depends on how often you ovulate. Some women with PCOS ovulate now and then, others not at all.

If you do not ovulate but want to become pregnant then fertility treatments may be recommended by a specialist and have a good chance of success. But remember, you are much less likely to become pregnant if you are obese. If you are obese or overweight then losing weight is advised in addition to other fertility treatments.

Metformin and other insulin-sensitising medicines

Metformin is a medicine that is commonly used to treat people with type 2 diabetes. This may help to counteract the underlying cause of PCOS.

Where to get more help?

In the UK there is a charity called Verity offers support for women with PCOS, for more information you may want to look at their website <http://www.verity-pcos.org.uk>

References

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Polycystic Ovary Syndrome, Long Term Consequences, Green-top Guideline No.33, Royal College of Obstetricians and Gynaecologists, November 2014.

Dr Mary Harding. 8th July 2016. Polycystic Ovary Syndrome, Women's Health, Patient's info. Retrieved from URL: <https://patient.info/health/polycystic-ovary-syndrome-leaflet>

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Any Comments, Compliments, Concerns or Complaints

If you have any other concerns please talk to your nurse, therapist or doctor. Our Patient Advice and Liaison Service (PALS) are available on 03033 306518 (Grimsby, Scunthorpe and Goole). You can also contact nlg-tr.PALS@nhs.net

As a Trust we value equality of access to our information and services, therefore alternative formats available on request at nlg-tr.interpreters@nhs.net

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