



Polycystic ovary syndrome (PCOS)

This leaflet is for women diagnosed with polycystic ovary syndrome (PCOS) and explains what your management options are.

What is PCOS?

Polycystic ovary syndrome (PCOS) describes a condition in which women may have menstrual (period) irregularities or excess male hormones, with or without cystic appearance of the ovaries, which are revealed on an ultrasound scan.

How common is PCOS?

PCOS affects an estimated 10% (one out of every 10) women of childbearing age. There is no cure for PCOS; however, its symptoms may be controlled by changes in lifestyle and medications.

What causes PCOS?

Doctors are still not entirely clear why some women have polycystic ovaries. There is often a hereditary link and a link with diabetes in the family. PCOS is thought to be due to a hormonal imbalance where the ovaries produce a little too much male sex hormone. This in turn results in further hormonal abnormalities, which can be measured on blood tests.

What are the symptoms of PCOS?

Women with PCOS may have some of the following symptoms:

- **Menstrual irregularities:** PCOS often comes to light during puberty due to period problems, which affects around 75% (3 out of 4) women with PCOS. Infrequent, irregular or absent periods are all common variations; many finding their periods particularly heavy when they do arrive. The period disturbance is a sign that there is a problem with regular monthly ovulation. Heavy, abnormal bleeding can also be caused by PCOS but other problems must be ruled out.
- **Infertility:** While women with PCOS produce follicles, which are fluid-filled sacs on the ovary that contain an egg, the follicles often do not mature and do not release an egg each month. It is these immature follicles that create the cysts. PCOS is a common cause of infertility due to irregular or absent ovulation. It is not usually 100% absolute, and some women with PCOS will ovulate normally, some will ovulate less frequently (leading to a delay to pregnancy) and some will not ovulate at all. Therefore, many women with PCOS are able to conceive, especially with the help of a fertility specialist, and to carry successful pregnancies to term. There are a number of possible treatments to help induce ovulation.

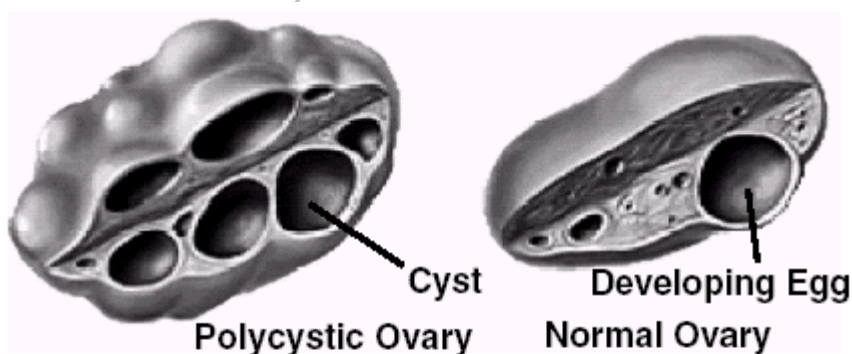
- **Hirsutism (excess hair):** Excess hair growth, such as on the face, chest or abdomen. Hair that was previously light in colour and texture can be stimulated by male sex hormones in the system which are present because of the hormone imbalance, resulting in darkening and coarsening of hair particularly in the moustache and beard areas and around the nipples.
- **Alopecia (male-pattern baldness or thinning hair):** Hair thinning is more common on the top of the head than at the temples.
- **Acne / oily skin:** Oil production is stimulated by overproduction of male sex hormones. Acne can be annoying, particularly on the face, chest or back.
- **Obesity or weight gain:** Many, but not all, women with PCOS struggle with their weight. Commonly a woman with PCOS will have what is called an apple figure where excess weight is concentrated heavily in the abdomen, similar to the way men often gain weight, with comparatively narrower arms and legs. This is a double-edged sword for women with PCOS. Weight gain often worsens the other symptoms of PCOS and unfortunately, the hormone changes associated with PCOS may make weight loss more difficult.

How is PCOS diagnosed?

Part of the diagnosis is showing some of the symptoms mentioned above. Other tests to confirm the diagnosis include:

- **Ultrasound scan:** This is usually done as an internal scan, meaning a small ultrasound probe is placed just inside the vagina, giving the best views of the ovaries and pelvic organs. In PCOS, the ovaries are found to have multiple, small follicles around the edge of the ovary. These follicles are only a few millimetres in size, do not in themselves cause problems and are partially developed eggs that were not released. A PCOS diagnosis cannot be made entirely on the basis of ultrasound alone as not all women with PCOS have increased numbers of follicles.
- **Blood tests:** A couple of blood tests will assist in making the diagnosis - one to check the level of androgens (male hormones), such as testosterone. Another test will measure the hormones involved in egg development.

The diagnosis of PCOS is made on the basis of a combination of clinical observation and the results of investigations.



The many cysts in a polycystic ovary are follicles that have matured but, due to abnormal hormone levels, never released eggs. In a normal ovary, a single egg develops and is released each month.
(Source: <http://www.onhealth.com>).

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PCOS: diabetes, insulin and long-term risks

In recent years it has become clear that PCOS is closely related to a problem with insulin. Insulin is a hormone released from the pancreas after a meal and it allows the organs of the body to take up energy in the form of glucose. In PCOS there is a 'resistance' of cells in the body to insulin, so the pancreas makes more insulin to try and compensate. The excessively high levels of insulin have an effect on the ovary, causing a rise in androgen (testosterone) levels and preventing ovulation.

One study found that 30% (3 out of 10) slim women with PCOS have insulin resistance; however, it affects as many as 75% (3 out of 4) those who are overweight. This explains why overweight women with PCOS are more likely to suffer with excessive hairiness and infertility related to not ovulating

Longer-term risks of PCOS

The long-term risks of PCOS are related to both the insulin problem and the high androgen levels. High levels of insulin are associated with an increased risk of developing type 2 diabetes mellitus. Women with PCOS are three times more likely to get type 2 diabetes than women without PCOS. The best way to reduce the risk of type 2 diabetes mellitus is through careful food choices, exercise, and weight loss in overweight individuals.

Irregular or infrequent periods over a long period of time lead to an increased risk of cancer of the lining of the uterus (endometrial cancer). This is, in part, due to high levels of the hormone oestrogen, which over-stimulates the lining of the uterus. Absence of ovulation, and the resulting progesterone deficiency, also contributes to this risk. The key to reducing risk is to make sure to have some kind of menstrual "bleed" in which the lining of the uterus is shed at least every three months, preferably more often. This can be accomplished through the use of birth control pills or progesterone/progestins for period induction.

What are the treatment options?

Weight loss

If you are overweight, as little as 5% weight loss can regulate periods, lead to more ovulatory cycles, improve hairiness, reduce the risk of heart disease and lower insulin levels. To lose weight safely and keep it off you should ideally see a dietician to discuss the optimum diet. Getting weight into the normal range and maintaining it there should be considered a lifelong process, rather than a short-term fix. Regular exercise will help ensure that you maintain the weight you lose.

Control of irregular periods

As mentioned previously, irregular and heavy periods can occur due to problems with ovulation. Whilst it would seem that restarting ovulation would be the best treatment, this is generally reserved for when a pregnancy is desired. The ovarian stimulation drugs to do this have other side effects, making their long-term use inappropriate.

Excess weight is a cause of menstrual problems in both women with and those without PCOS. Extra oestrogen is made in fat tissues and this interferes with ovulation and leads to over-stimulation of the lining of the uterus and heavier periods. Weight reduction will improve cycle control and reduce the heaviness of menstrual flow.

Periods may be controlled by the use of the contraceptive pill, which is most suitable for women under the age of 35 who also require a good form of contraception. The other type of drug used is a progesterone-like hormone. Progesterone is the main hormone of the second half of the menstrual cycle, maintaining its length and helping reduce the heaviness. Progestagens are taken as tablets in a cyclical way, for example between days 12-26, the exact type and timing depending upon the woman's individual cycle problem.

Some women have no periods at all, and either the contraceptive pill or cyclical progestagens are advisable to avoid the risk of endometrial cancer. Around 6 periods per year is adequate to protect against this.

Insulin-sensitising drugs – Metformin

As previously explained, PCOS is associated with insulin resistance, leading to the body producing excessively high levels in an attempt to compensate. This higher level of insulin is known to cause abnormal cholesterol and lipid levels, obesity, irregular periods, higher levels of androgens, infertility due to disturbance of ovulation and an increased likelihood of diabetes. Metformin is a type of drug known as an 'insulin-sensitising agent', which improves the sensitivity of the body to insulin in turn reducing the excessively high insulin. Since it does not stimulate production of insulin, it does not cause hypoglycemia.

There are several studies that have been carried out and published concerning the use Metformin as a treatment for PCOS. These suggest that it may well be useful in several areas: helping weight reduction, improving irregular periods, reducing androgen levels, leading to ovulation, improving hirsutism and possibly reducing the risk of miscarriage. The most common side effects during treatment are diarrhoea, nausea, vomiting and abdominal bloating. Starting with a low dose and building up to the desired maintenance level may help. Usually symptoms lessen over time and go away with long-term use (usually after 3-4 weeks at the same dose). If diarrhoea and nausea continue, you should make sure to take the medication in the middle of a meal.

The studies that are available concerning the use of insulin-sensitising drugs are very hopeful and will may pave the way for a longer-term treatment for this disease, which can affect many different areas of a woman's life.

Treatment of hirsutism (hairiness)

This is usually due to above average levels of androgens – the male hormones that are normally present in women at low levels. Some women do not find the excess hair a problem, particularly if it does not affect their face, or it is blonde in colour. Sometimes excess hairiness is not abnormal and is a racial or genetic variation. Initial treatments include bleaching and electrolysis. If these do not produce an acceptable result, drugs may be used to reduce the high androgen levels, if that is the cause. **These drugs do not make you fertile and in fact could harm the baby. It is essential that you do not get pregnant while taking antiandrogens.**

- **Dianette:** This is a form of contraceptive pill that contains oestrogen and Cyproterone acetate, an antiandrogen. It is quite effective in reducing excessive hair growth and very effective in the treatment of acne. It has the same side effects as the oral contraceptive pill, e.g. increased risk of blood clots, weight gain, mood swings and fluid retention.
- **Yasmin:** This is a form of contraceptive pill that contains oestrogen and drospirenone. It is quite effective in reducing excessive hair growth and very effective in the treatment of acne. It

has the same side effects as the oral contraceptive pill, e.g. increased risk of blood clots, weight gain, mood swings and fluid retention.

- **Vaniqa** (not available on the NHS locally): This is a cream that inhibits hair growth. It is only licensed to be used on the face. It is effective in reducing hair growth in 7 out of 10 women who use it. Hairs become finer and grow slower so you do not need to remove them as much. It usually takes effect within 8 weeks of use. It is applied to the 'hairy' parts of your face twice a day after washing your face. Side effects include worsening acne or an allergic skin rash.
- **Spironolactone**: This water tablet has also been shown to reduce excess hair growth. However, it frequently causes erratic periods, so is often given with a low dose contraceptive pill. The dose starts at 50mg a day, increased to 100mg a day 2 weeks later then up to 200mg a day two weeks after that. Your GP should check your blood potassium 1 week after starting Spironolactone and 1 week after each dose increase as it can occasionally cause high potassium levels. It can make your periods come on more frequently. To avoid that, once you are on 200mg a day, take it for three weeks then give yourself a week off, then repeat the treatment (similar to taking an oral contraceptive pill)
- **High dose Cyproterone acetate**: This is very effective in treating hirsutism. It is taken on days 5-15 of the menstrual cycle, in combination with an oral contraceptive pill. You should have a monthly bleed. If your periods stop then you must let us know so we can reduce the dose of the drug. High dose Cyproterone acetate may rarely cause problems with liver function, and so regular blood tests are advised. More common side effects include tiredness, weight gain, mood changes and reduced sex drive.

All hirsutism treatments must be continued for 8-18 months before a response can be expected, due to the slow rate of hair growth. At that time, electrolysis or laser therapy can be performed to remove the unwanted hairs already present, and less return growth can be expected.

Of note, although we do not know of any long term ill effects from the above treatments, none are officially licensed for the treatment of PCOS.

Infertility

Polycystic ovary syndrome is found in around 70% (7 out of 10) women who have ovulation difficulties leading to infertility. This is more common in women who are overweight, and as a first-line treatment, weight reduction can be very successful in restarting spontaneous ovulation. The amount that needs to be lost is less than most women might expect – around 5% of the current weight is associated with an increased number of ovulatory cycles. If despite weight loss and medications like metformin the fertility is not restored, then women may require specialist fertility treatment.

- **Clomifene**: This is usually the first line fertility treatment. It is recommended for women with PCOS who are trying to get pregnant. Clomifene encourages the monthly release of an egg from the ovaries (ovulation). The majority of women can be successfully treated with a short course of clomifene, taken at the beginning of each cycle for several cycles.
- If these are not successful, you may be offered **injections to stimulate the ovaries** or **in vitro fertilisation IVF** treatment. Neither of these treatments are likely to be successful in women who are overweight.

- **Surgery:** A minor surgical procedure called laparoscopic ovarian drilling (LOD) may be a treatment option for fertility problems associated with PCOS that do not respond to medicine. Under general anaesthetic, your doctor will make a small cut in your lower tummy and pass a long, thin microscope called a laparoscope through into your abdomen. The ovaries will then be surgically treated using heat or a laser to destroy the tissue that is producing androgens (male hormones). LOD has been found to help to correct PCOS hormone imbalance and can restore the normal function of your ovaries.

Further information

The UK PCOS support group can be found on www.verity-pcos.org.uk

More information about PCOS can be found on www.nhs.uk/conditions/polycystic-ovary-syndrome-pcos/

Contact us

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To find out more about our Trust visit www.royalberkshire.nhs.uk

Please ask if you need this information in another language or format.

RBFT Centre for Diabetes and Endocrinology, July 2003
Reviewed: January 2025. Next review due: January 2027.