

Polycystic Ovary Syndrome (PCOS)

A PATIENT'S GUIDE

Polycystic ovary syndrome (PCOS) is a common hormonal disorder among girls and women during their reproductive years. Normally, women make small amounts of “male” hormones (called androgens), such as testosterone, but women with PCOS produce slightly higher amounts. This hormone imbalance causes an assortment of health problems, such as irregular menstrual periods, too much hair on the body and face (hirsutism), and a very large number of follicles (small fluid-filled sacs where eggs develop) on the ovaries. These many follicles look like cysts, which is where the term “polycystic” comes from.

This guide for patients comes from The Endocrine Society's 2013 practice guidelines for physicians about the detection and treatment of PCOS.

Who gets PCOS?

Women and girls who are obese are more likely to have PCOS. It also seems to run in families.

Most often, PCOS symptoms first occur around the start of menstruation, but some women do not get symptoms until their early or mid-20s. Symptoms like excess facial hair and male-pattern baldness can continue even after a woman goes through menopause.

What causes PCOS?

The cause of PCOS remains unknown. There may be more than one cause.

The main problem in this condition is a hormone imbalance. There also is a link between PCOS, obesity, and resistance to insulin, the hormone that carries sugar from the blood into our cells. Many women with PCOS have too much insulin in their bodies because the insulin does not work as well as it should.

What are the signs and symptoms of PCOS?

- Menstrual problems:
 - Fewer menstrual cycles (less than 9 periods per year)
 - Lack of periods (amenorrhea)
 - Unpredictable heavy menstrual bleeding
- Infertility (trouble getting pregnant) due to not ovulating
- Excess or unwanted hair growth on your face and body
- Thinning hair on your scalp
- Weight gain or obesity, often around your waist

- Skin problems:
 - Acne on your chest, back, and face
 - Skin tags—small flaps of excess skin—on your neck and armpits
 - Dark, thick patches of skin on your neck, armpits, or groin, or under your breasts
- Depression or anxiety
- Poor sleep

Not all women with PCOS have all these problems. Each person may have a different mix of these features. Also, other conditions may cause some of these health concerns. For these reasons, PCOS can be hard to diagnose.

Which conditions mimic PCOS?

Before doctors diagnose PCOS, they must first rule out or exclude other conditions with similar symptoms. This is why they call PCOS “a diagnosis of exclusion.”

SOME CONDITIONS THAT MIMIC POLYCYSTIC OVARY SYNDROME (PCOS)

| Condition | What it is | Features similar to PCOS |
|--------------------------------|---|--|
| Thyroid disease | Overactive or underactive thyroid gland | Irregular menstrual cycle |
| Prolactin excess | The body makes too much of the hormone prolactin | <ul style="list-style-type: none"> • Male-type hair growth in women • Irregular periods or lack of periods |
| Cushing syndrome | The body makes excess cortisol hormone | <ul style="list-style-type: none"> • Weight gain • Depression • Too much hair in women • Abnormal menstrual periods |
| Congenital adrenal hyperplasia | Inherited disorder that causes the body to make too little cortisol and too much male hormone | <ul style="list-style-type: none"> • Acne that is severe and early (before the teen years) • Infertility or decreased fertility • Facial hair in women and teen girls • Infrequent or absent menstrual periods |

How does a doctor diagnose PCOS?

Experts suggest that a diagnosis of PCOS requires the following:

- **Women.** Have at least two of these features:
 - Excess male hormones
 - Problems with ovulation
 - Many pearl-sized follicles on one or both ovaries
- **Teen girls.** Have both of these features:
 - Excess male hormones
 - Infrequent or absent menstrual periods, mainly lasting more than two years after the start of menstruation
- No other cause of the symptoms

Your doctor will take your medical history, asking about your health and menstrual cycle. A physical exam should include measuring your height, weight, and waistline, and looking for skin and hair problems.

No single test detects PCOS. Sometimes a blood test is needed to measure your hormone levels. To check for a large number of follicles, your doctor may order an ultrasound (usually done through the vagina), which uses sound waves to take pictures of the ovaries. Most teens will not need an ultrasound because it is common to have many follicles at that age.

What tests do you need after diagnosis?

Women with PCOS may need tests to screen for health problems that occur more often in PCOS. These conditions can be serious and include

- **Diabetes, high blood glucose (sugar) levels.** After diagnosis of PCOS, you should have an oral glucose tolerance test. This fasting blood test checks for diabetes and prediabetes (high blood sugar levels that are not yet diabetes). Your doctor may want you to take this test every three to five years, but you may need to repeat it sooner if you gain a lot of weight or have symptoms of diabetes, such as frequent thirst or urination.
- **Heart and blood vessel (cardiovascular) disease.** Because women with PCOS are at increased risk for high blood pressure, you should have your blood pressure checked at each doctor's visit. After finding out you have PCOS, you may have a fasting blood test to check for high cholesterol and high levels of other blood fats (lipids), such as triglycerides. Lipids also can be too high in women with PCOS.
- **Endometrial (uterine) cancer.** Abnormal uterine bleeding is a possible sign of endometrial cancer, so tell your doctor if you have unexpected spotting between periods or bleeding after menopause. An ultrasound can find abnormalities such as increased thickness of the uterine lining, which may lead to a biopsy to rule out precancer and cancer. But the guidelines do not recommend routine ultrasound screening for women with PCOS who do not have symptoms.
- **Sleep apnea.** Obstructive sleep apnea is when you stop breathing for short times while asleep. Symptoms include

loud snoring, daytime sleepiness, and sometimes waking up gasping or short of breath. If you have any of these problems, your doctor may want you to do an overnight sleep study. It is important to treat sleep apnea because it raises the risk for diabetes, stroke, and heart disease.

- **Pregnancy complications.** Women with PCOS are more prone to gestational (pregnancy) diabetes, pregnancy-induced high blood pressure, and birth of a premature baby. Women who are overweight are more likely to have these complications. Talk to your doctor about what tests you need before you try to become pregnant and during pregnancy.

What is the treatment for PCOS?

Some medications can relieve symptoms of PCOS, and others rebalance your hormones.

The first treatment for most women and teens with PCOS is birth control pills or a contraceptive skin patch or vaginal ring. These medications contain female hormones that help protect the uterus and prevent unpredictable bleeding. They also lower androgen levels, reducing excess hair growth and improving acne. Birth control pills also prevent your uterine lining from thickening, thus lowering the risk of uterine cancer.

Ask your doctor if this treatment option is right for you. Some women should not take the pill due to specific risk factors.

Other treatment options for PCOS symptoms and complications are

- **Lifestyle changes.** If you are overweight, you should lose weight by exercise and eating a healthy, low-calorie diet. Weight loss lowers your risk for diabetes and heart disease. Losing weight also improves menstrual function and may help some women ovulate naturally.
- **Metformin.** This medicine helps lower blood sugar levels. It is a suitable treatment for women with PCOS who have prediabetes or diabetes and who cannot lose weight through lifestyle changes. Metformin also seems to help menstrual cycles become more regular. It may be an option for women who cannot or do not want to take the pill. (Metformin does not prevent pregnancy.)
- **Fertility drugs.** Clomiphene citrate is most often the first treatment for women who do not ovulate and want to get pregnant. You take this drug by mouth for five days to stimulate ovulation. Another treatment to induce ovulation is letrozole.

More treatments are available to reduce unwanted hair growth, acne, and (to a lesser degree) scalp hair loss. Find more information about these treatments in the Hormone Health Network's fact sheet on PCOS.

There is no cure for PCOS. But with proper treatment and lifestyle changes, you can improve most of your symptoms and reduce your chance of developing health problems related to PCOS.

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Note to health care professionals: This patient guide is based on, and is intended to be used in conjunction with, The Endocrine Society's clinical practice guidelines (available at www.endo-society.org/guidelines/index.cfm).