

## Polycystic Ovarian Syndrome (PCOS)

### *Signs, symptoms, and treatments*

#### What is PCOS?

*Polycystic ovarian syndrome* (PCOS) is a disorder that affects up to 1 in 10 women of *reproductive age* (the years between the first menstrual period and menopause). PCOS changes how a woman's hormones work, which can interfere with monthly ovulation. That can lead to infertility. When a woman has trouble getting pregnant because she's not ovulating regularly, PCOS is the most common reason.

PCOS can also cause:

- Insulin resistance (see pages 2 and 3)
- Over-production of male hormones
- Tiny cysts around the ovaries (*polycysts*), due to the imbalance of hormones

Treating PCOS can help:

- Preserve or restore fertility
- Reduce unpleasant symptoms, both inside the body and those you can see
- Reduce the increased risk of type 2 diabetes and heart disease that comes with having PCOS



*When a woman has trouble getting pregnant because she is not ovulating regularly, PCOS may be the reason.*

#### Why does PCOS happen?

We do not know the exact cause of PCOS. Many factors work together for PCOS to occur.

#### Genetic Causes

One of these factors is *genetic*, which means it can run in families. Many women with PCOS have female relatives with PCOS, even if they were never diagnosed. When looking at your own family history, look for female relatives on both your mother's and father's sides who had problems with fertility or irregular periods, or both.

You might wonder if there is one "PCOS gene" that puts women at higher risk of having the disorder. It is more likely that many genes affect someone's risk of developing PCOS.

## Other Factors

Even though PCOS is a genetic disorder, there are other causes, too. These may include:

- Changes in the ovaries
- Problems such as abnormal blood sugar (glucose), blood pressure, or blood cholesterol
- Lifestyle factors such as an unhealthy diet and not enough exercise

## How does PCOS affect my body?

Many organs and glands are involved in keeping your hormones working well. These organs and glands are called the *endocrine system*.

## Reproductive Hormones

Your *pituitary gland* is a pea-shaped gland that sticks out from your *hypothalamus* at the base of your brain. The hypothalamus controls the pituitary gland.

The pituitary gland secretes several hormones. Two are important in PCOS:

- *Lutenizing* hormone (LH) helps your ovaries develop and release eggs.
- *Follicle stimulating* hormone (FSH) helps eggs mature.

Problems with either the hypothalamus or the pituitary gland can affect ovulation and cause missing or irregular periods.

When the ovaries do not get the right amounts of LH and FSH from the pituitary gland:

- Eggs may not mature and ovulate properly
- Ovaries may produce less estrogen and more male hormones, like testosterone

This can cause the ovaries to develop tiny cysts on their surface. The technical term for this is *polycystic*.

## Insulin Resistance

Most women with PCOS have *insulin resistance*, which is a serious problem. Insulin is a growth hormone that we need to survive. Without insulin, energy from the food we eat (in the form of glucose) cannot get into our body's cells. Our cells need insulin for our bodies to function normally.

In insulin resistance, glucose cannot get into our cells. When this happens, the organ that produces insulin (the *pancreas*) makes more and more insulin, trying to force our cells to let glucose in. Over time, the pancreas can wear out and produce too little insulin. This can lead to *diabetes*.

When our cells are “starving” for glucose, we may feel tired. Even worse, having extra glucose in our bloodstream can damage our blood vessels and the tissues that need nourishment from our blood. Having extra insulin in our blood can make it easier to gain weight, especially in the belly area, where having too much fat is especially unhealthy. Insulin resistance can also cause some of the skin symptoms that are common with PCOS.

## **What are signs and symptoms of PCOS?**

Not all women with PCOS have the same signs and symptoms. This is why some women can have PCOS for years and not know it.

Most PCOS signs and symptoms are caused by too much insulin or too much of the male hormones. Physical signs can include:

- Extra hair growth on the face, chest, and back.
- Thinning of the hair on the crown of the head.
- Tendency to gain weight around the waist, resulting in an “apple shape” instead of the typical female “pear shape.” For women, a waist measurement of more than 35 inches may be a sign of PCOS.
- Acne or other skin symptoms, such as flaky skin or swollen sweat glands in the armpits and groin.
- “Dirty looking” raised velvety areas on the skin, often on the back of the neck, the armpits, the groin area, and beneath the breasts. This is one symptom of insulin resistance.
- Other skin symptoms caused by insulin resistance can include skin tags, rough elbows, and rough, reddened hair follicles on the upper arms.

Women with PCOS may also have:

- Menstrual periods that are irregular or absent. When periods do happen, they may be heavy.
- A hard time getting pregnant.
- Problems with blood sugar (glucose). This may include high blood glucose, or episodes of low blood sugar, which can make you feel tired and weak.
- Strong cravings for carbohydrates.
- High blood pressure.
- High LDL (“bad”) cholesterol, low HDL (“good”) cholesterol, and/or high triglycerides (blood fats).

## How is PCOS diagnosed?

Women with PCOS do not all have the same signs and symptoms. Most are overweight or obese, but about 1 in 3 are thin or average weight. Some have male-pattern hair growth or hair loss; some do not. Some struggle with acne; others do not. Some have normal periods, while others rarely have a period.

These different symptoms can make it hard to diagnose PCOS. Health care providers who have more experience treating PCOS patients are often more skilled at recognizing and diagnosing PCOS.

But, there are specific signs your health care provider can check to help diagnose PCOS. These include:

- Checking to see if you have *hyperandrogenism* (too much *androgen*, a male hormone). This is diagnosed with blood tests or by physical signs.
- Asking you about your menstrual periods. With PCOS, you might have irregular periods (*oligo-ovulation*) or no periods at all (*anovulation*). A woman with PCOS usually has fewer than 8 periods a year.

Another sign of PCOS is having tiny cysts on your ovaries (*polycystic ovaries*). About 3 out of 4 women with PCOS have these cysts. An ultrasound can be done to check for them. You do not need to have these cysts on your ovaries to be diagnosed with PCOS.

## What should I do if I have PCOS symptoms?

If you think you may have PCOS, talk with your health care provider. Your provider will give you a full medical exam and will want to know:

- Your menstrual history
- Your weight history
- If any of your family members have had PCOS, diabetes, or *metabolic syndrome* (a group of risk factors that increase the risk for diabetes and other health conditions)
- What medicines and dietary supplements you use
- If you use birth control medicines, since these can lower male hormones and make PCOS harder to diagnose
- Results of other medical tests, such as blood tests and ultrasounds

Even though PCOS can be hard to diagnose, our understanding of PCOS is growing, and so are the treatment options.

## How does PCOS affect fertility?

Nearly 75% of women with PCOS (75 out of 100) have problems with fertility. For pregnancy to occur, your body must ovulate. The changes in your hormone levels that PCOS causes interfere with ovulation. Some women do not find out they have PCOS until they seek medical help for infertility.

If you have taken oral contraceptives for years, you may not know whether you are ovulating each month. Oral contraceptives also lower male hormone levels. This can “hide” PCOS symptoms as long as you are taking the medicine.

When a woman with PCOS stops taking oral contraceptives to try to get pregnant, she may start having some of the symptoms that have been hidden, such as irregular periods and strange skin and hair symptoms.

## What are complications of PCOS?

Women with PCOS:

- Are at higher risk of developing *gestational diabetes*, a type of diabetes that sometimes occurs during pregnancy. This can harm the health of both mother and baby.
- May be more likely to have a miscarriage than women without PCOS.
- Tend to have higher LDL (“bad”) cholesterol, lower HDL (“good”) cholesterol and higher triglycerides (blood fats) than women without PCOS. Each of these is a risk factor for heart disease.
- Have a higher risk of developing heart disease and type 2 diabetes:
  - About 30% to 40% of women with PCOS (30 to 40 out of 100) have *pre-diabetes*, a condition that sometimes occurs before diabetes.
  - Women with PCOS are 4 to 7 times more likely to have a heart attack than women of the same age who do not have PCOS.
- Have a higher risk of some cancers:
  - Women who miss a lot of periods do not shed the *endometrium* (lining of the uterus) each month. This increases the risk of endometrial cancer.
  - High blood sugar caused by insulin resistance may cause cancer cells to grow.

Weight is also a risk factor when linked with PCOS. Overweight or obese women who have PCOS have a greater risk of heart disease than lean women who have PCOS. This is especially true for women who have an “apple shape” and store a lot of body fat around their abdomen and waist. This adds more risks to your health than excess fat around your hips and thighs.

## **What can I expect at my health care visit?**

Your provider will do a full health exam. You may have blood tests for:

- Levels of lutenizing hormone (LH) and follicle stimulating hormone (FSH), the hormones that your pituitary gland produces
- Levels of estrogen, which your ovaries secrete (release into your body)
- Levels of male hormones, including testosterone, which your ovaries secrete, and DHEA-sulfate, secreted by your adrenal glands
- Levels of blood sugar (glucose) and insulin, including:
  - Fasting levels of blood glucose
  - Fasting levels of insulin in your blood
  - Oral glucose tolerance test, which measures your blood glucose levels at certain times after you drink a sweet beverage
  - Hemoglobin A1C, a blood test that shows average blood glucose over the last 3 months
- Levels of cholesterol and fats (triglycerides) in your blood

To help rule out other health conditions, your provider may also do blood tests to check:

- Levels of *thyroid-stimulating hormone* and *prolactin* (another hormone secreted by your pituitary gland)
- Levels of vitamin D
- Your liver function

## **What are treatment options for PCOS?**

If you are diagnosed with PCOS, your health care team will work with you to develop a treatment plan to manage your symptoms. The plan will also treat underlying hormonal imbalances that are causing the symptoms and increasing your risk of diabetes and heart disease. Your plan will likely include both healthy lifestyle changes and medicine.

### **Medicines**

Your health care provider may prescribe drugs that:

- Help your insulin work better and lower the insulin levels in your blood
- Lower your blood glucose
- Balance your reproductive hormones (oral contraceptive pills)
- Lower your LDL (“bad”) cholesterol and triglycerides
- Regulate your blood pressure

To treat symptoms like acne, excess body hair, and thinning hair on your head, you may also receive *anti-androgen* medicines to reduce male hormones. Oral contraceptives may also help reduce these symptoms.

### **Lifestyle Changes**

Medicines can help reduce PCOS symptoms, effects, and complications. But, eating a healthy diet and being physically active can help you do all of these things and more.

A healthy lifestyle can help you:

- Improve fertility
- Reach and maintain a healthy weight and body fat levels
- Lower your risk of type 2 diabetes, heart disease, and cancer

Think of medicine as a tool that can give healthy lifestyle changes an extra boost where it is needed.

### **Be an Active Partner on Your Health Care Team**

Treatment for PCOS can be complex, because it involves both your reproductive system and your endocrine system. You may have many health care providers on your health care team, including:

- Your primary care provider – for general health care needs and initial diagnosis and management
- An *obstetrician/gynecologist* – for general reproductive health, fertility issues, and care during pregnancy
- A *reproductive endocrinologist* – for treating imbalances in the reproductive hormones and restoring fertility
- A *registered dietitian* – for help managing PCOS, controlling weight, and improving fertility with nutrition and lifestyle therapy
- A *dermatologist* – for treating skin symptoms (if needed)
- A mental health therapist – for help with the feelings that can come with infertility and coping with a chronic health problem

Your doctors can prescribe medicine and your registered dietitian can give you advice about eating for improved health. But for this medicine and advice to be effective, you will have to follow your treatment plan. To make sure you understand your plan:

- Take notes during office visits.
- Ask questions. You might be concerned about drug side effects or you may be unsure how to get the right balance of carbohydrates. Ask about anything you do not understand or are concerned about.

## Living with PCOS: Mind Matters

Many symptoms of PCOS, especially those that can be easily seen, can affect your self-esteem and body image. If your fertility is affected and you want to become pregnant now or plan to in the future, it can be very upsetting. It is also scary to know that you have a health condition that increases your risk of diabetes and heart disease.

Some women are relieved to finally have a diagnosis, because they no longer have to wonder why they were having all those different symptoms. Others feel shocked, nervous, or frightened. Either way, it may help to remember:

- **You are not alone.** One in 10 women has PCOS.
- **A diagnosis is the first step to better health.** Now that you know what your health problem is, you can start to treat it. Our understanding of this syndrome and how to treat it is constantly growing.

## To Learn More About PCOS

To find out more about eating for health when you have PCOS, ask for our handout, “PCOS Nutrition.” The handout also contains a list of books and websites specifically about PCOS and healthy eating.

### Books

- ***The PCOS Workbook: Your Guide to Complete Physical and Emotional Health.*** Angela Grassi (2009).
- ***Before Your Pregnancy: A 90-Day Guide for Couples on How to Prepare for a Healthy Conception.*** Amy Ogle, MS, RD, and Lisa Mazullo, MD (2011).

### Websites

- Polycystic Ovarian Syndrome Association, Inc.: [www.PCOSsupport.org](http://www.PCOSsupport.org)
- SoulCysters: [www.soulcysters.com](http://www.soulcysters.com)
- Women’s Health: [www.womenshealth.gov](http://www.womenshealth.gov)

### Questions?

Your questions are important. Call your doctor or healthcare provider if you have questions or concerns.

Nutrition Clinic: 206.598.6004