Polycystic Ovarian Syndrome
Fact Sheet

Prepared by: esa endocrine society of australia

What is PCOS?

Polycystic ovarian syndrome (PCOS) is a hormonal disorder, affecting around 1 in 10 women of reproductive age [1]. It is more common in Aboriginal and Torres Strait Islander women, where it affects around 1 in 5 women [2].

Women with PCOS produce higher levels of certain hormones. These include insulin and a group of hormones called androgens, which includes the hormone testosterone.

What are polycystic ovaries?

PCOS is often confused with the term 'polycystic ovaries'. 'Polycystic ovaries' is a term used to describe how ovaries look on an ultrasound scan. If an ovary looks as though it has more than 20 follicles, it may be described as 'polycystic' These follicles are fluid filled sacs containing developing eggs.

Polycystic ovaries are fairly common, found in around 25% of women. They are mostly discovered by accident when having an ultrasound for other reasons, as they do not appear to cause any symptoms.

You can have 'polycystic ovaries' on an ultrasound scan without having Polycystic Ovary Syndrome. You can also have Polycystic Ovary Syndrome without having 'polycystic ovaries' on your ultrasound.

What causes PCOS?

The cause of PCOS is still unclear, however genetics appear to play a strong role. Women with PCOS are more likely to have a female family member with this condition.

What are the symptoms and signs of PCOS?

The symptoms and signs of PCOS can differ between women, and vary in severity and change over time. Symptoms and signs can include:

- Irregular periods (occurring less than 8 times per year or less than 21 days apart)
- No periods (amenorrhoea)
- Excess hair growth on face and body (hirsutism)
- Loss or thinning of hair on scalp (alopecia)
- Acne (pimples)
- Skin tags (thickened areas of skin, most often occurring in armpits, neck and on bra line)
- Darkened patches of skin on the neck or under the arms (acanthosis nigricans)
- Difficulty managing weight
- Mood changes
- Anxiety
- Depression
- Low body image
- Insulin resistance
- High cholesterol levels and altered blood lipid (fat) profiles

These signs and symptoms can lead to other health issues, including:

- Fertility problems or difficulties getting pregnant
- Gestational diabetes (when pregnant)
- Sleep apnoea and sleep difficulties
- Eating disorders and disordered eating
- Body image issues
- Depression, anxiety and mood changes
- Increased risk of type 2 diabetes
- Increased risk of cardiovascular disease (heart attacks, heart disease, stroke)
- Increased risk of endometrial cancer

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The symptoms of PCOS are caused by the following hormonal imbalances in women with PCOS.

1. Insulin

Insulin is the hormone that controls blood sugar levels by letting sugar enter cells in the body. Without insulin, most cells are not able to use sugar to power their functions. Under normal circumstances, insulin is released in response to a rise in blood sugar levels. This causes cells around the body to absorb glucose (sugar) from the blood, so that blood sugar levels remain within a normal range.

The majority of women with PCOS are 'insulin resistant'. In insulin resistance the body is partially 'resistant' to the effects of insulin. This means that higher insulin levels are required to control blood sugar levels and allow cells to use sugar as a source of energy. High insulin levels contribute to weight gain and cause the ovaries to produce more androgens.

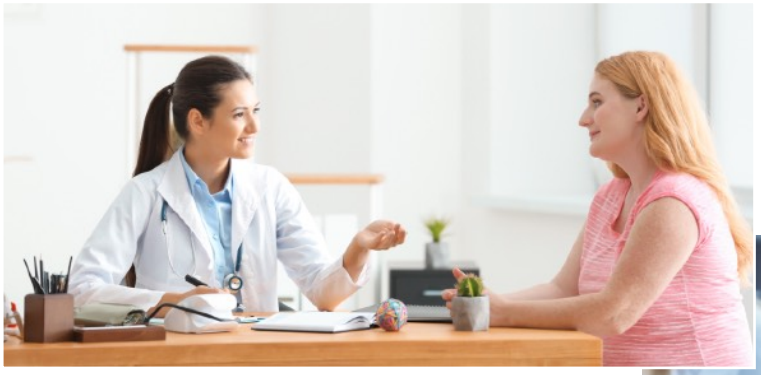
Lifestyle factors, such as poor diet and lack of physical activity, can worsen insulin resistance. Insulin resistance is most common in women with PCOS who are overweight but is also common in women with PCOS who are within a healthy weight range.

When the body can no longer produce enough insulin to control blood sugar levels, Insulin resistance develops into Type 2 diabetes.

2. Androgens

Androgens, such as testosterone, occur in men and women. Although women have much lower levels of testosterone than men, women in fact have higher testosterone levels than estradiol levels (estrogen). So although testosterone is often thought of as being a 'male' hormone, it is also an important hormone in women. In women androgens are made by the ovaries and adrenal glands.

In women with PCOS, the high levels of insulin cause the ovaries to produce excess androgens. Androgens cause several symptoms of PCOS, including excessive facial and body hair, alopecia (thinning scalp hair) and acne. High levels of androgens can also cause disruptions to the menstrual cycle, causing irregular periods, amenorrhoea and difficulties getting pregnant.



How is PCOS diagnosed?

Before making a PCOS diagnosis, your doctor will need to rule out other conditions that could also cause your symptoms.

A diagnosis of PCOS depends on your age and a number of criteria being met [3].

For women 20 years or older, two of the following criteria are required for a diagnosis.

i. Irregular periods (defined as cycles either more frequent than every 3 weeks or less frequent than every 5 weeks), or no periods.

ii. High androgen levels in the blood or symptoms of high androgen levels, such as excess hair growth or acne.

iii. An ultrasound of the ovaries showing polycystic ovaries – either a large number (20+) of partially developed eggs in either ovary, or the size of one or both ovaries appears large.

If, however, you meet the first two criteria above, then a diagnosis can be made with no need to have an ovary ultrasound.

For women younger than 20 years, (or less than 8 years since their first period) an ultrasound is not recommended. This means that a diagnosis of PCOS requires the presence of both the first two criteria.

Irregular periods are quite common in the first few years after periods begin. This can make diagnosing PCOS difficult in young women. Sometimes a firm diagnosis cannot be made until adulthood. Follow-up assessments are recommended so that a clear diagnosis can be made.

1. Medical History and Physical Examination

Your doctor will ask you questions about your health, symptoms, menarche (age when you had your first period), period length and regularity and medical history, including if you take any medications or use any hormonal contraceptives (such as the pill, minipill, Mirena). They will also ask you questions about other health conditions, your family history and your current lifestyle behaviours. This information is important to identify signs that might support a diagnosis of PCOS and rule out any other conditions.

2. Blood tests

A blood test will be used to measure the level of testosterone in your blood, as well as sex hormone binding globulin (SHBG), a protein that binds to testosterone. Your testosterone level and SHBG may be reported as the 'free androgen index (FAI)'.

Your doctor will conduct other blood tests to help support a diagnosis of PCOS or rule out other conditions. This may include:

- Other androgens or factors that influence androgen activity (dehydroepiandrosterone sulphate (DHEAS) and androstenedione).
- Hormones that regulate the menstrual cycle (follicle stimulating hormone; FSH), luteinising hormone (LH) and estradiol (a type of estrogen).
- Hormones that regulate thyroid function (thyroid stimulating hormone; TSH)
- Pituitary gland hormones (prolactin)

For these tests, a small amount of blood is taken and sent to a laboratory for testing.

It is important to note that hormone levels are affected by the contraceptive pill. If you are taking the pill, you will need to stop for 3 months before your blood test to obtain an accurate result. Other methods of contraception will be needed during this time. Your doctor can help advise you about suitable options.

What do the results mean?

- High androgen levels can support a diagnosis of PCOS if other criteria are also present (see above).
- Normal androgen levels do not rule out a diagnosis of PCOS if other criteria are present (see above).

3. Ultrasound

An ultrasound may not be needed, depending on whether the other criteria have been met. For women under 20 years, an ultrasound is not recommended for a PCOS diagnosis [3].

An ultrasound is used to visualise (take images) of the ovaries and surrounding areas. These images can be used to identify the number of 'cysts' on the ovaries, where eggs are partially developed, as well as the size of the ovaries.

Ultrasounds use high frequency waves to produce images. These waves are emitted from a transducer that transmits images directly to a monitor. Ultrasounds do not use radiation, so are safe with no harmful side effects. Ultrasounds are performed by your doctor or a sonographer in a clinic or specialty radiology imaging centre.

There are two main methods of ultrasound that are used to visualise the ovaries.

- **Transvaginal ultrasound** – This is an internal examination, only used on women who have been sexually active. For this method, the transducer is shaped like a wand. During the scan, you will lie on an examination bed undressed from the waist down and covered by a sheet. The sonographer covers the transducer with a condom and lubricating gel, before inserting it gently into the vagina. Once in place, the sonographer rotates the transducer to obtain images. This method can be uncomfortable but should not be painful. This method usually takes 20-30 minutes. The images obtained using this method are much clearer than an abdominal ultrasound.
- **Abdominal ultrasound** – This is a painless external examination. For this scan, you will be asked to lie face up on an examination table. Your clothes may need to be adjusted to expose your lower belly region. A gel is then applied to the skin on your lower abdominal region (belly) to help improve the quality of the images. A handheld transducer (shaped like a microphone) is then pressed against your abdomen and moved gently around to capture images of your ovaries. The gel is removed at the end of the ultrasound. This method usually takes around 10-20 minutes.

What do the results mean?

- More than 20 cysts identified on either ovary suggests polycystic ovaries.
- Enlargement of one or both ovaries may suggest polycystic ovaries.

Polycystic ovaries can support a diagnosis of PCOS if other criteria are also present (see above).

How is PCOS treated?

There is no cure for PCOS, however, PCOS can be managed through lifestyle modifications and with appropriate medications.

The goals of managing PCOS are to reduce symptoms, improve physical-, emotional- and mental health, prevent long-term health conditions and improve quality of life. For women seeking to become pregnant, management of PCOS may also include assistance with fertility and providing support during pregnancy. Your health care team will work with you on the symptoms that are most important to your health and quality of life.

Because PCOS can have many symptoms, it is important to have a multidisciplinary health care team. Depending on your symptoms, this may include your GP, an endocrinologist, a gynaecologist, a dietician, a psychologist, exercise physiologist or physiotherapist, a dermatologist and fertility specialists.

Lifestyle behaviours

Physical activity and diet - Taking part in regular physical activity (e.g. walking, household chores, sports) and having a healthy and balanced diet have many benefits for PCOS. Around 150 minutes of moderate to vigorous physical activity every week is recommended [4].

These benefits include:

- Improving your emotional and mental health
- Controlling your blood sugar levels, which can help to reduce insulin resistance.
- Helping to regulate your periods
  Improving your fertility and chance of getting pregnant
- Managing your weight
- Having healthier skin
  Feeling fitter

There is no specific diet recommended for women with PCOS. However, women with PCOS who need to lose weight should aim for a calorie intake of 1200 calories per day, and 250 minutes a week of moderate-vigorous physical activity [4]. It is more important to find physical activities that you enjoy doing, and eat healthy, tasty foods, to promote healthy living over the longer term.

Hair removal – Excess hair can be removed through various methods, including waxing, threading, laser therapy, electrolysis and hair removal (depilatory) creams.

Psychologist/Counselling

It is very important to be aware of and look after your emotional and mental health. Depression, anxiety and low mood are common in women with PCOS. PCOS is also associated with body image concerns, eating disorders, and sexual difficulties. Seeking help from your GP or a psychologist will help overcome these problems.

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Medications

For some women, medications are sometimes needed to help manage PCOS.

The oral contraceptive pill - The 'pill' can improve period symptoms and reduce androgen levels. In turn, this can reduce excess facial and body hair growth, improve acne and reduce scalp hair loss.

Progestin containing treatments e.g. MIRENA, Implanon, mini pill, Primolut. These treatments are sometimes used in women who have infrequent periods to prevent an abnormal build-up of the lining of the uterus (endometrial hyperplasia) and in the longer term prevent endometrial cancer.

Insulin-sensitising medications e.g. metformin. Insulin sensitising medications can help prevent weight gain, help stabilise blood glucose levels, reduce androgen levels and avoid progression to diabetes. They can also be used by women with PCOS with amenorrhoea (no periods) to initiate menstrual cycles (periods). Metformin works best in combination with lifestyle changes, and is not recommended as a substitute.

Anti-androgen medications e.g. spironolactone (Aldactone), cyproterone acetate (Androcur). These medications reduce androgen production and block the effects of androgens, so can reduce symptoms of androgen excess, such as excess facial and body hair growth, improve skin health (reduce acne) and reduce scalp hair loss. These drugs are teratogenic, which means they can cause birth defects if used while pregnant. For this reason, they are not suitable for use when pregnant or trying to get pregnant. When taking these medications, you must be using contraception.

Isoterinoin e.g. Roaccutane. This medication is used to treat severe acne. In Australia, isoterinoin can only be prescribed by a skin specialist. This medication is teratogenic, which means it can cause birth defects if used while pregnant. For this reason, it is not suitable for women who are pregnant or trying to get pregnant.

Fertility medications e.g. letrozole, clomiphene citrate. These medications can help restore periods and increase the chance of a successful pregnancy. IVF is an option for women who do not fall pregnant using these medications.

PCOS and pregnancy

Women with PCOS who have no periods or irregular periods can have trouble falling pregnant without assistance. The first line management of infertility in PCOS is to restore periods, through lifestyle intervention and/or medication [5]. Sometimes more help will be required using assisted reproductive treatments (ART) like in vitro fertilisation (IVF) [5].

Women with PCOS often take longer to become pregnant compared to other women [6], however on average have the same number of children as women without PCOS [5].

It is important to remember that women with PCOS can fall pregnant spontaneously, so contraception should be used to avoid an unwanted pregnancy.

It is a good idea to discuss your plans to get pregnant with your health care team, so you can receive the best health care advice and support, and manage any infertility issues.

Once pregnant, it is a good idea to advise your health care team about your pregnancy, so they can offer additional support to optimise your health and help you manage any changing symptoms across pregnancy.

PCOS can increase the risk of several pregnancy complications, including high blood pressure, gestational diabetes and preterm birth [7]. It is important to advise your obstetrician about your PCOS early in pregnancy so they can provide additional support and monitor your and your baby's health.

Ongoing management of PCOS

Women with PCOS will need to see their doctor regularly to monitor their health. At these visits, your doctor will review your symptoms, check your blood pressure and may conduct a blood test to check your glucose and cholesterol levels.

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FAQs about PCOS

Can PCOS go away on its own or be cured?

Unfortunately, no. The symptoms of PCOS can be managed to improve quality of life. It is important to discuss the issues affecting you with your health care team, as women with PCOS experience PCOS differently.

Do missed or irregular periods affect my chances of getting pregnant?

Missed or irregular periods make it more difficult for any woman to get pregnant, regardless of PCOS. Making lifestyle changes and taking any required medications can help your periods become more regular, which will improve your chances of getting pregnant.

Will I need IVF to get pregnant?

Not necessarily. Many women with PCOS get pregnant naturally, or with the help of medications that stimulate ovulation. For those who do not become pregnant, IVF is an option. Losing even a little weight can improve the chances of pregnancy – both naturally and with IVF.

It is important to note that women with PCOS have the same number of children as women without PCOS, however may need help to get pregnant.

Will my symptoms go away after menopause?

Unfortunately, PCOS doesn't go away after menopause, however your symptoms may change. Menopause and PCOS have many symptoms in common (e.g. irregular periods, thinning hair), so it can be difficult to identify when you are approaching menopause.

Does having PCOS mean I will get diabetes?

Women with PCOS are more likely to develop type 2 diabetes, and gestational diabetes than other women, due to the insulin resistance. This risk increases if you are obese or have a family history of Type 2 diabetes. Your diabetes risk can be reduced through lifestyle changes, weight loss and in some cases, medication.

Questions to ask your doctor

Seeing your doctor or having a medical problem can be stressful. It often takes time for information to sink in and it is very common to feel overwhelmed by what is happening.

Sometimes it is helpful to write down questions for your doctor before you go.

Some questions that might be relevant to you are:

- Do I have PCOS or polycystic ovaries?
- Do I need to see different specialists or other health professionals?
- What is the best way to treat my symptoms?
- Do I need medications for my PCOS?
- What are my choices for medication?
- Does my medication have any side effects?
- What should I expect with my symptoms?
- Do I need another appointment?

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To Find an Endocrinologist near you visit: http://www.hormones-australia.org.au/find-an-endocrinologist/

For more information and support, visit…

Your doctor (GP)

An Endocrinologist: https://www.hormones-australia.org.au/find-an-endocrinologist/

AskPCOS.org is a web based App designed especially for women and girls who think they may have PCOS, those who already have a diagnosis, and for those supporting women with PCOS. It has been designed based on best available evidence, developed by the Monash Centre for Health Research and Implementation, Monash University and Monash Health. https://www.askpcos.org/

Jean Hailes: https://www.jeanhailes.org.au/health-a-z/pcos On this site, you will find information on PCOS, as well as videos and other resources.

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About This Fact Sheet

The content on this page has been medically reviewed by Dr Rosie Worsley.

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