



This information is adapted from materials produced by the Monash Centre for Health Research and Implementation (MCHRI) that were informed by the [International evidence-based guideline for the assessment and management of Polycystic Ovary Syndrome \(PCOS\) 2018](#).

## What is PCOS?

Polycystic ovary syndrome (PCOS) is the most common hormonal condition affecting women in their reproductive years.

Around one in seven women have PCOS which can cause a range of symptoms such as; irregular periods (menstruation), skin and hair changes and for some women, difficulties getting pregnant.

PCOS is mainly due to a hormonal imbalance rather than a disease of the ovaries. The two main hormones associated with PCOS are **insulin** and **androgens**. (Hormones are chemical messages made in one part of the body that affect other parts of the body). Because of these hormones associated with PCOS, the ovaries and eggs struggle to function normally.

The names Polycystic Ovaries and Polycystic Ovarian Syndrome (PCOS) suggest that there are many “cysts” on the ovary **but this is not correct**. When an ultrasound is performed on the ovaries, they may appear to have many dark circular areas. These dark areas on the ovary are **follicles** and are due to under-developed eggs. They are quite common, particularly in young women. They are not, as the name suggests, ovarian cysts. In PCOS, the eggs inside these follicles have stopped developing part-way along their journey and they don't mature, so they are not released during ovulation each month. This causes irregular periods and can create some difficulties getting pregnant. These follicles do not cause pain and there is **no known link** between these follicles in PCOS and larger true ovarian cysts (which may need surgery).

If the hormone levels associated with PCOS can be reduced or controlled, the ovaries can often function normally.

## What causes PCOS?

The causes of PCOS are not fully understood. **Genetics** (family inheritance), **hormones** that are increased during our development in the uterus (womb) before birth, and **lifestyle factors** all play a role.

### Genetics

Women with PCOS are 50 percent more likely to have a mother, aunt or sister with PCOS than women without PCOS. The condition is more common in women with particular ethnic backgrounds such as: Asian, Aboriginal and Torres Strait Islander, African (Somali, Ethiopian, Eritrean and



Sudanese) and Caucasian European. We also know that our lifestyle – including what we eat and how active we are - can make the symptoms of PCOS more or less severe.

### Hormones

The symptoms and signs of PCOS occur because of an imbalance of two hormones: Insulin and Androgen. Being an unhealthy weight affects these hormones and increases the severity of the PCOS symptoms. For women who are overweight, losing some weight helps to reduce these symptoms.

### What are the symptoms of PCOS?

PCOS is called a syndrome which means it is characterised by a range of symptoms.

The symptoms of PCOS differ widely between individuals. They affect the three main areas: **reproductive, metabolic** and **psychological health**.

An important fact about PCOS is that symptoms will vary not only between individuals, they also vary at different stages of life.

This is the range of symptoms that adolescents and women with PCOS may experience. It is important to note that not all of these symptoms are experienced by all women, and that effective treatments are available for these symptoms:

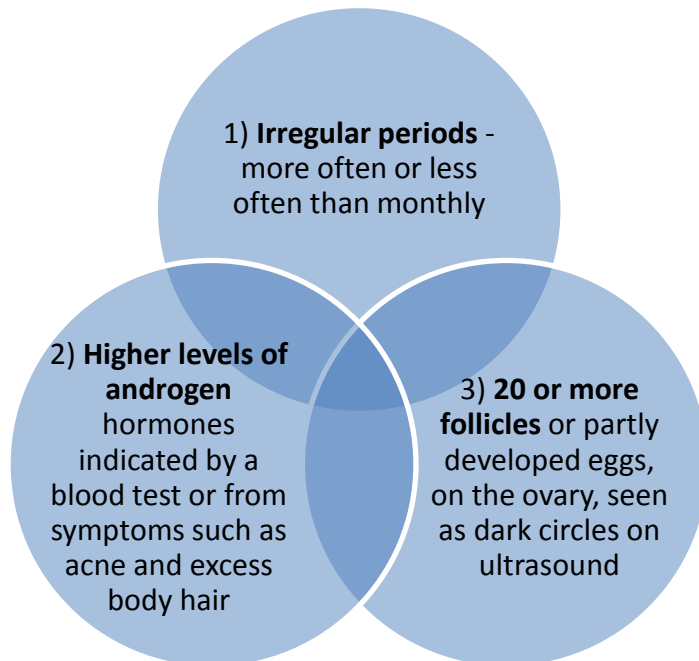
- periods (menstruation) that are irregular (more or less often than monthly)
- no periods or less than eight periods per year
- periods with heavy or light bleeding
- excess hair growth on face, stomach, back
- loss of hair on the top of the scalp
- acne (pimples) that may be very severe
- weight gain
- difficulties getting pregnant
- some health challenges during pregnancy
- emotional challenges (depression and/or anxiety)
- increased risk of diabetes
- sexual health challenges
- low self- esteem
- poor body image
- impact on the quality of life

You may experience PCOS quite differently to another adolescent or woman with PCOS. Therefore your care and management needs to be right for you.



## How is PCOS diagnosed?

If women have **two of these three criteria**, it is likely that they will be diagnosed with PCOS:



Other conditions that can appear similar to PCOS need to be checked by your doctor and excluded before a diagnosis of PCOS can be confirmed.

PCOS is difficult to diagnose in young women in the first few years after their periods start. In the first year, periods are often irregular and by the second year periods normally settle into a regular pattern. In young women with PCOS however, this does not happen. Instead periods are either very close together (less than 21 days) or far apart (more than 45 days). After the third year if they remain less than 21 days or more than 35 days, this suggests PCOS.

PCOS is also difficult to diagnose in women who are taking the contraceptive pill as this medication alters hormone levels. If an accurate diagnosis is needed, the pill needs to be stopped for three months beforehand (and an alternative method of contraception used).



## Tests for diagnosing PCOS

A doctor may order a **blood test**, and maybe an **ultrasound**.

### **Blood test**

A blood test will measure the level of male type hormones (androgens, also called testosterone) and to exclude other conditions. The signs and symptoms of PCOS can be similar to other conditions so it is very important to rule these out before a diagnosis can be established.

### **Ultrasound**

Ultrasound is only needed for women who don't have criteria 1) and 2). A vaginal ultrasound provides a picture of the ovaries. If there are 20 or more follicles (fluid filled sacs) on either ovary, this is consistent with a diagnosis of PCOS.

Ultrasounds are not recommended for women younger than 20 years of age or for adolescents within eight years after starting their periods. This is because results may not be reliable, as it is common for young girls to have a large number of follicles on their ovaries. Ultrasound is also not used for young women who are not yet sexually active.

## **Fertility issues for women with PCOS**

Overall, women with PCOS have a similar number of children, as women without PCOS.

While 30 percent of women with PCOS have no problem, around 70 percent have some difficulties getting pregnant.

A range of PCOS factors may decrease fertility such as increased levels of hormones, increased weight (Body Mass Index ([BMI in the unhealthy weight range](#))) and lifestyle factors including poor nutrition and low levels physical activity. However, medical management and a healthier lifestyle can increase the chances of a successful pregnancy.

If it is possible, and part of their life plan, it is recommended that women with PCOS consider starting their family early. For those women who may have difficulties becoming pregnant, starting earlier offers more time to try a range of fertility treatment options. Also, the risk of age-related infertility begins to increase for all women around the age of 35 years, which is another reason why trying to become pregnant earlier is recommended if you are in a position to do so.

Women with PCOS have an increased risk of developing gestational diabetes due to the presence of insulin resistance. To reduce your risk it is important to eat a healthy diet, to be as active as possible during your pregnancy and monitor and gain the healthy recommended weight. It is also important to be screened by having an Oral Glucose Tolerance Test before and then during the pregnancy to see how well your body is managing glucose.



## Ovulation

Women's two **ovaries** lie on either side of the uterus (also known as womb). Each ovary is about the size of a coin. The ovaries store eggs (ova) and also make various hormones. Hormones are chemicals that are made in one part of the body, pass into the bloodstream and have an effect on other parts of the body. The main hormones that are made in the ovaries are oestrogen and progesterone. These hormones help with the development of breasts and are the main controllers of the menstrual cycle. The ovaries also normally make small amounts of male hormones (androgens) such as testosterone.

Ovulation normally occurs once a month when an egg (ovum) is released into a fallopian tube. Before an egg is released at ovulation, it develops within a little swelling of the ovary, called a **follicle**. Each month several follicles start to develop but normally just one fully develops and releases its egg from the ovary into the fallopian tube. After the egg is released from the ovary it travels down the fallopian tube to the uterus where it may be fertilized by sperm if sexual intercourse has occurred. This is when a pregnancy can happen.

## PCOS affects ovulation

PCOS-related infertility is caused by higher levels of androgens and insulin that can affect the menstrual cycle (periods) and prevent ovulation. Between 70 to 80 percent of women with PCOS report having periods less than monthly (less than eight periods per year).

In women with PCOS, their follicles often stop developing in the usual way, due to higher levels of hormones. This results in many immature, small follicles remaining within the ovaries. An egg may be released or no eggs are released (anovulation). These follicles look like dark circles on ultrasound. They are not cysts as the name Poly Cystic Ovarian Syndrome implies.

Ovulation can stop completely or it can occur irregularly. This can make it more difficult for women with PCOS to become pregnant. It also means that pregnancy can occur, so **contraception is still needed for women with PCOS who don't want to be pregnant.**

## Managing weight through a healthy lifestyle

**Insulin** is another hormone that affects a woman's ability to become pregnant.

Insulin's most important job is to help control the sugar (glucose) levels in the body by helping to get it into the cells to be used for energy, or to send it into storage, if not needed. This way the level of glucose in the blood is kept steady.

- Insulin works like a key to let glucose (energy) into the body cells
- In PCOS, many women have insulin resistance, where the cell will not let insulin work

properly, resulting in higher levels of insulin in the blood

- Higher insulin levels can make people gain weight easier and may increase appetite
- Higher insulin levels can eventually lead to diabetes



The good news for women with PCOS is that regular physical activity can help insulin work better and reduce insulin resistance significantly.

**Managing weight** has been shown to be an effective way to reduce insulin levels and increase the chances of pregnancy for women with PCOS. Even small weight loss (5 to 10 percent of overall body weight) combined with increased activity levels and a healthy diet can contribute to improved fertility and reduce the risk of complications during pregnancy.

For example, for a woman who weighs 80kg, 5 to 10 percent is 4 to 8 kg.

**Lifestyle changes have been shown to be the most effective treatment to increase fertility.**

When making changes to your lifestyle, it's best to avoid short term fad diets or changes you are unlikely to be able to maintain long-term. Make sure you are ready to change and that you have support around you. We know that partners who both decide to live a more healthy lifestyle - eat healthier food and be more active - have more success in reaching their goals.

Importantly, set small achievable goals that you can manage such as taking the stairs rather than the lift, increase your steps each day in other ways, try using a pedometer that counts your daily steps, swapping juice and other sugary drinks for water to reduce your sugar intake. Build these changes up slowly over time.

Women with PCOS who work closely with their health care providers gain valuable support to help them achieve their weight loss goals.

## Medical treatment options

Some women will need further medical support and can be referred by their GP to a fertility specialist for specific treatments. There are a range of **medications** that can be very effective in assisting women with PCOS to get pregnant. If these don't work, **injections** or **minor ovarian surgery** may help.

Most women with PCOS are likely to achieve pregnancy with medical support. If women are at an older age or are an unhealthy weight, their chances of a successful pregnancy can be affected.

There are other options available, mainly when a woman has additional causes of infertility as well as PCOS, or where the above options have failed. These include **Assisted Reproductive Technology (ART)**. ART includes treatments such as IVF (in vitro fertilisation). Assisted reproductive technology can be expensive and is not always successful. Also, being an unhealthy weight decreases the chances of a successful pregnancy when using ART. Women who adopt a healthier lifestyle before they start ART have a greater chance of pregnancy success.

Find out more about ART from the Victorian Assisted Reproductive Treatment Authority (VARTA) [website](#).



## Emotional wellbeing

Women with PCOS have an increased risk of emotional challenges such as anxiety and depressive symptoms. It is not clear why, but this may be due a combination of hormonal influences and dealing with the symptoms of PCOS.

PCOS is a condition that can challenges our ideas of femininity. Symptoms such as acne, weight gain, excess hair and difficulties getting pregnant may cause women to feel they do not fit the image of how females are supposed to look. These emotional challenges can be particularly difficult when individuals are unaware they have PCOS.

The overall quality of life for girls and women with PCOS can be reduced if they do not have both the knowledge about PCOS and the support they need to manage it. Your emotional health may be improved with support, education about PCOS and appropriate treatment. Also, the support from a range of health professionals such as doctors, psychologists, counsellors, exercise physiologists and the social support of family, friends and other women with PCOS, is very important.

Women with PCOS are strongly encouraged to monitor their own emotional health. One way to do this is by asking the following questions:

- Have I lost interest or pleasure in doing things I usually enjoy?
- Do I worry a lot about the way I look?
- Do I feel down, depressed or hopeless?
- Do I feel guilty, depressed or disgusted about my eating?

If you have answered yes to any of these questions it is important to seek help from a health professional. A doctor will provide support and if required, will refer you to a counsellor or psychologist who can give you specialised psychological support.

Research shows that for it can be difficult for some women to get motivated to start and stick with healthy lifestyle changes. This may be due to lack of progress in the past, emotional challenges, or a range of other reasons.

The good news is that evidence suggest ways to overcome some of these challenges. For example, women with PCOS who develop a support network are more likely to persist with a healthy lifestyle. A support network can be include health professionals (GPs, psychologists, dieticians, exercise physiologists and/or personal trainers) and social support such a friend, partner or family. Many women also find joining a network of women with PCOS helpful. This may be a local group or an online network (See **More about PCOS** for details of online support groups). It is important that you decide what works best for you.

It is worth remembering that progress is not always straightforward and may be more 'one-step forward and two-steps back' at times. Many things in our lives can stop our best efforts to be healthy, such as stress and emotional challenges. These can be hard to predict and can seem overwhelming at times. The important thing is to keep your eye on your goals and to keep going.

Some days you will succeed and others you will not but in the end you will make progress.



## More about PCOS

The [Monash Centre for Health Research and Implementation website](#) provides a comprehensive range of information for women with PCOS and for health professionals, including:

- videos from experts on all aspects of PCOS
- information for women [in easy to understand graphic formats](#)
- podcasts from women with PCOS and from experts
- information about Victoria's [Statewide Polycystic Ovarian Syndrome Service](#)

[The Polycystic Ovary Syndrome Association of Australia Inc \(POSAA\)](#) was formed in 1998, by a group of Australian women who found each other on an American-based PCOS website. POSAA is a 'self-help' association for women with PCOS and those who suspect they have it. The Association brings together women, their families and friends, and medical professionals interested in supporting the group and PCOS patients.

[Verity](#) is a UK based PCOS support network run by women with PCOS.

[PCOS Challenge](#): The National Polycystic Ovary Syndrome Association is the leading USA based non-profit patient support and advocacy organisation globally that is advancing the cause for women and girls with PCOS.

The [Victorian Assisted Reproductive Treatment Authority \(VARTA\)](#) provides independent information and support for individuals, couples and health professionals on fertility and issues related to assisted reproductive treatment. This includes IVF, surrogacy and donor-conception.

[Jean Hailes for Women's Health](#) is a not-for-profit Australian health promotion organisation that provides evidence-based PCOS information.

