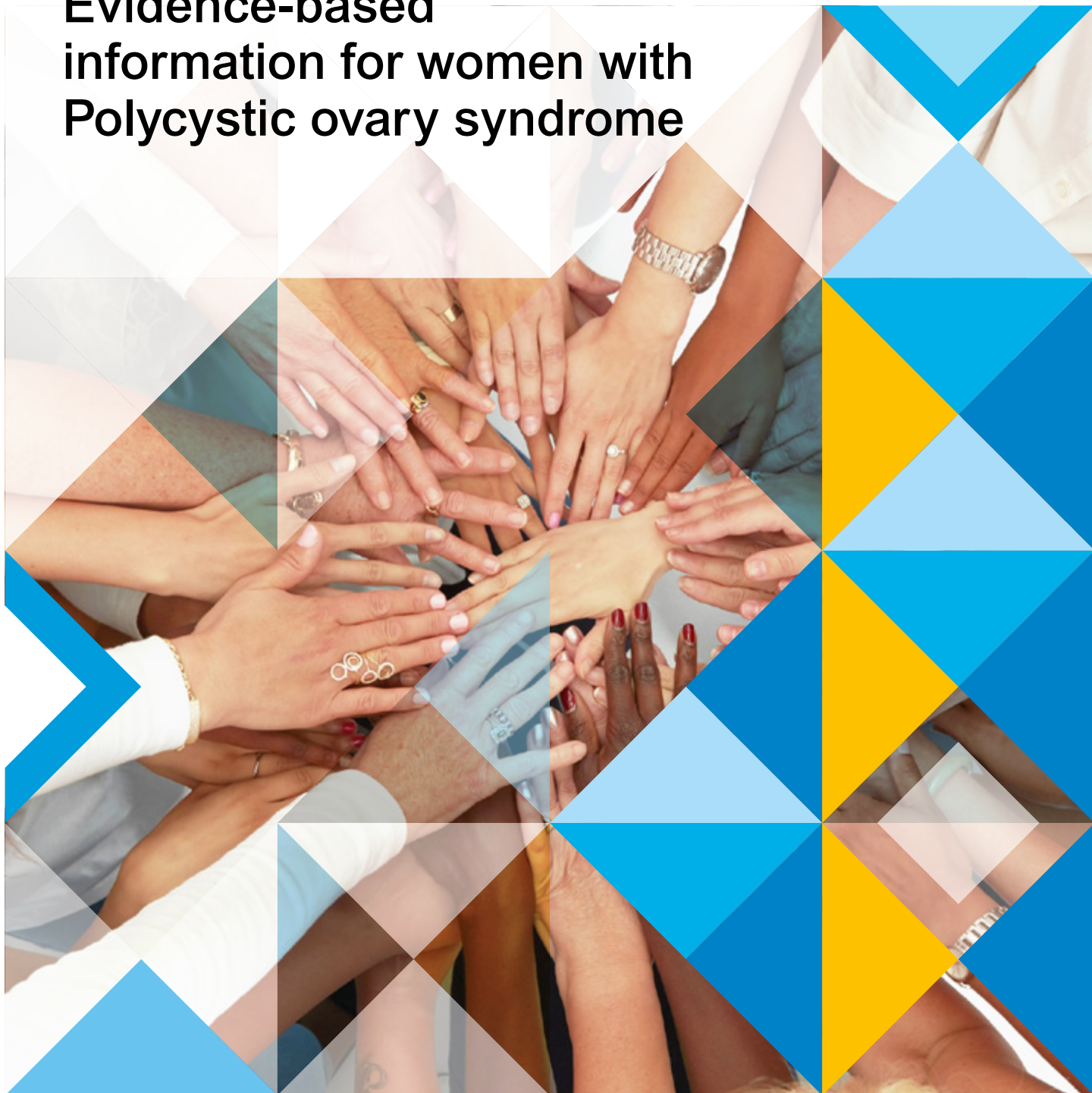


ASK PCOS

Evidence-based
information for women with
Polycystic ovary syndrome



This booklet is for girls and women with polycystic ovary syndrome (PCOS).
It is easy to read and provides the best available information about PCOS.
Good information is critical to achieving the best health outcomes.




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Acknowledgement of the funding

This booklet is based on the International evidence-based guideline for the assessment and management of polycystic ovary syndrome 2018. It forms part of an extensive range of resources developed for health professionals and women with polycystic ovary syndrome (PCOS). We are grateful to the Australian Government for funding the PCOS research translation program. To find out more about this program and access PCOS resources please go to: www.monash.edu/medicine/sphpm/mchri/pcos

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Polycystic ovary syndrome (PCOS) key messages

- PCOS is common and you are not alone
- PCOS can have features that change over the longer-term
- PCOS affects individuals differently and treatments need to be tailored to your needs
- There are short and long-term health impacts
- Learning as much as you can about PCOS is important
- Treatment can reduce symptoms and the risk of later complications
- Lifestyle management improves all aspects of PCOS
- Effective treatments are available including when you wish to have a family
- Evidence-based information and support is available
- A focus on being as healthy as you can now and moving forward is important

What is PCOS?

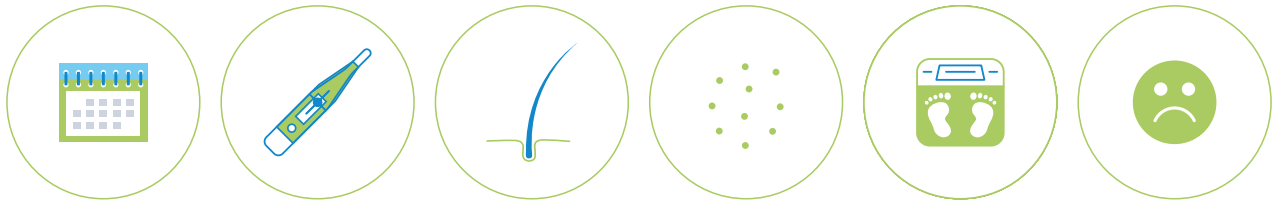
Polycystic ovary syndrome (PCOS) is a common hormone condition.

Hormones are chemical messages in the blood. In PCOS, two hormones (androgens and insulin) are responsible for the symptoms related to PCOS. Around one in seven girls and women have PCOS.

What causes PCOS?

The known causes of PCOS are; family inheritance, hormones that are increased during our development in the womb before birth, and lifestyle.

What are the symptoms of PCOS?



The symptoms of PCOS vary between women and at different life stages.

The range of symptoms individuals with PCOS may experience include:

- periods (menstruation) that are irregular (more or less often than monthly)
- 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 in getting pregnant
- emotional challenges (depression and/or anxiety)
- increased risk of diabetes with earlier onset
- sexual health challenges
- low self esteem
- poor body image
- impact on quality of life

Not all of these symptoms are experienced by all women.

It is important to note that effective treatments are available for these features.

How is PCOS diagnosed?

To get a diagnosis of PCOS you need two of the following three;

- 1 Periods that are more or less frequent than monthly
- 2 Symptoms such as acne (may be severe) and increased hair growth (face, stomach, back) or a blood test showing higher levels of androgen hormones
- 3 Ultrasound (image) of your ovaries (showing more than 20 follicles). You do not need to have an ultrasound if you have 1) and 2). For younger women within 8 years of periods starting 1 and 2 are needed for diagnosis. For adult women if 1 and 2 are present, the diagnosis is made once other causes are excluded. In adults if only 1 or 2 are present then an ultrasound can be performed. Ultrasounds are not recommended in young women.

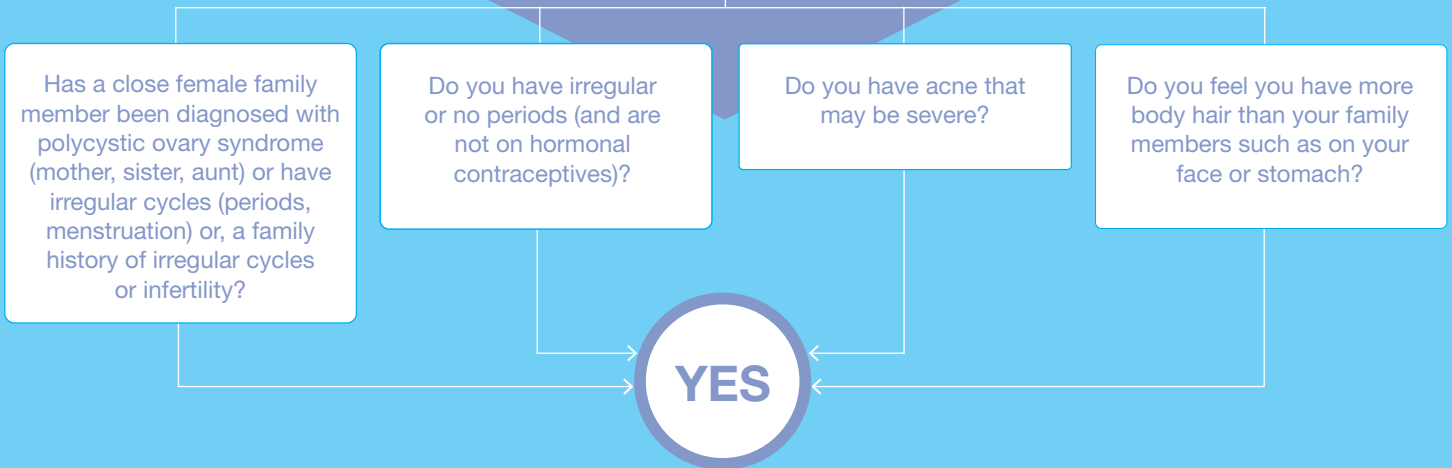
Your doctor will also exclude other diseases before making a PCOS diagnosis.

You can take the quiz in the fact sheet on page 3 to see if you need to discuss PCOS with your doctor.

What is PCOS & do I have it?

Polycystic ovary syndrome (PCOS) is a common condition but with good support, it is very manageable.

Answer the following quiz:



If you answered yes to one or more of these questions, see your doctor

Symptoms

The symptoms of PCOS vary between women. The range of symptoms you may experience are:



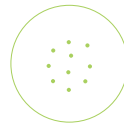
Irregular periods that are more or less than monthly or no periods



Delays in getting pregnant



Excess hair growth on face, stomach, back and loss of hair on the top of the scalp



Acne, darkened skin patches



Weight gain (that needs monitoring) and increased metabolic and diabetes risk



Impact on emotional wellbeing, self-esteem and body image

Diagnosis

There is some variation in what symptoms or signs for a PCOS diagnosis. We require only two of the following three signs to diagnose a woman with PCOS:

#1

Periods less regular – more or less often than monthly

#2

Higher levels of androgen hormones found from a blood test or symptoms such as excess body hair

#3

If needed in adults – if 1 or 2 alone are present then the appearance of partly formed eggs (fluid filled sacs called follicles) will be observed on ultrasound (greater than or equal to 20 follicles per ovary).

**This ultrasound is only needed if 1) and 2) are not found and is not recommended in younger women*



The AskPCOS App provides comprehensive, high quality PCOS information and support tools that are based on the latest evidence.

Emotional well-being and PCOS

Emotional challenges



Women with PCOS have a greater risk of emotional challenges such as anxiety and depressive symptoms. These challenges may be due to a combination of hormonal influences and dealing with the symptoms of PCOS.

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. Feeling different may affect overall quality of life for girls and women with PCOS. Women with PCOS also say they experience challenges with sexual relationships.

Anxiety and depression

Anxiety involves persistent and sometimes extreme feelings of fear or worry. Women with PCOS commonly experience higher levels of anxiety. Anxiety can interfere with the quality of your life and may require the support of health professional and in some cases treatment. Anxiety disorders are treatable and a number of effective treatments are available. It is important to seek help early.

Depression is a common and serious medical illness that negatively affects how you feel, the way you think and how you act. Fortunately, it is also treatable. Depression causes feelings of sadness and/or a loss of interest in activities that you once enjoyed. It can lead to a variety of emotional and physical problems and can reduce your ability to function. It is very important to recognise the signs of depression and seek help early.

What you can do?

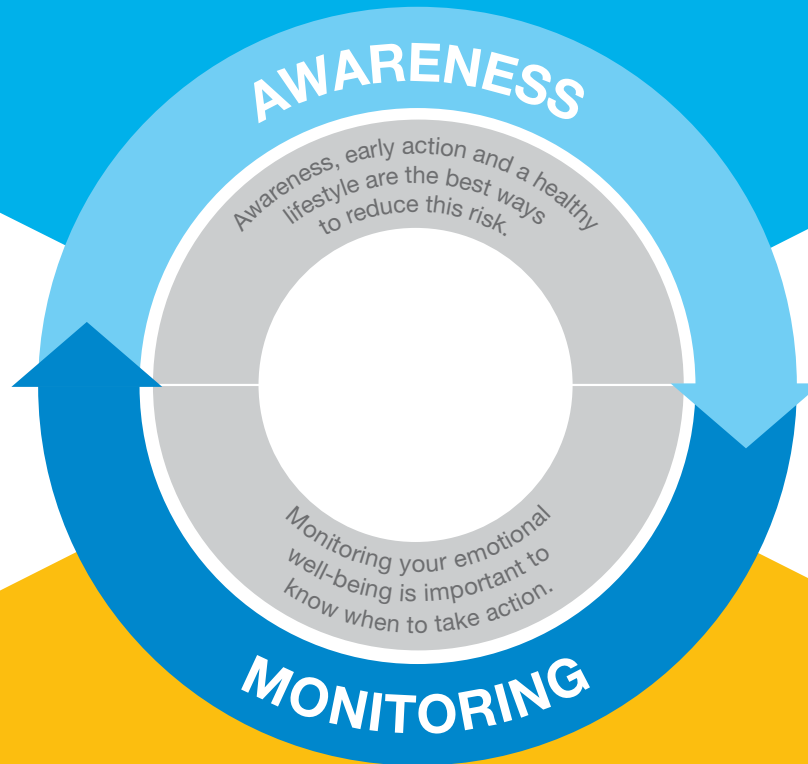
Your emotional health may be improved with good social support, education about PCOS and appropriate treatment. A healthy lifestyle is also very important to improving your emotional outlook. Regular activity has been shown to boost brain chemicals that help to reduce your risk of emotional challenges. Also, getting the support of a range of health professionals such as doctors, psychologists, counsellors, exercise physiologists and other women with PCOS, is very important.

How can I monitor my emotional well-being?

- Ask yourself the questions on the fact sheet on page 5 to monitor your emotional well-being.
- Take action early if answered 'often' to any of the questions.
- Talk with your doctor about options to assist you.

Emotional Well-being and PCOS

Women with PCOS have an increased risk of anxiety, depression, poor self-image and low self-esteem



If you answer often to any of the questions below, start to take action

Over the last 2 weeks, how often have you been bothered by the following problems?



Feeling down, depressed, or hopeless



Little interest or pleasure in doing things



Feeling nervous, anxious or on edge



Not able to stop or control worrying

Reduce the risk and severity of these challenges:



Talk to your GP. He/she may give you a referral to other health professionals if needed.



Educate people close to you about PCOS and the challenges you may face to your emotional well-being.



Seek support of family, friends and health professionals to assist you in achieving good emotional well-being.



Be as active as possible. At least half an hour per day of activity.



Eat a healthy diet, most of the time.

Lifestyle and PCOS



A healthy lifestyle is vital for all women with PCOS and is the best approach to reducing the severity of PCOS symptoms.

A healthy lifestyle includes:

- being as active as possible
- eating a balanced, nutritional diet
- not sitting for long periods by getting up hourly to move and stretch
- stopping smoking and reducing alcohol consumption, if needed
- monitoring your weight and avoiding any excess weight gain, no matter what your starting weight



Diet

There is no single diet that works better than a balanced, healthy diet.

A healthy diet includes:

- eating fresh fruit and vegetables
- eating lean meats
- cutting out or reducing foods such as sugary drinks and foods high in sugar, salt and unhealthy fats
- making water your main drink



Weight

Many women with PCOS are at risk of being an unhealthy weight (body mass index - BMI over 25) – BMI is calculated from weight (kg) / height x height (metres)

If you are an unhealthy weight aim to;

- monitor your weight regularly if comfortable to do so
- seek the support of a health professional
- follow the healthiest lifestyle you can and aim not to put on more weight
- be as active as you can
- reduce overall food intake
- monitor how your emotions may influence your eating patterns

Lifestyle and PCOS

Move at every opportunity



Take advantage of opportunistic activity

- Take the stairs
- Park further away
- Walk to the shops instead of driving
- Sit less, move more



Preventing excess weight gain is important in managing PCOS

How much activity is ideal?

Weight maintenance for adult women	Weight loss for adult women	Adolescents
150+ mins / week Moderate activity OR 75+ mins / week Vigorous activity	300+ mins / week Moderate activity OR 150+ mins / week Vigorous activity	60+ mins / day Moderate to Vigorous activity
OR a combination of both	OR a combination of both	
Include weight training 2x per week	Include weight training 2x per week	Include weight training 3x per week

Healthy/prevention of weight gain

- Weight loss for women who are at an unhealthy weight
- Monitor weight and waist circumference
- Eat a balanced, healthy diet
- Pay attention to portion control
- Reduce soft drink, fruit juice and sugar sweetened drinks

Healthy lifestyle helps to:

- Maintain or reduce weight
- Improve how you feel about your body
- Make insulin work better and prevent diabetes
- Make your periods more regular
- Improve energy levels
- Improve your fertility
- Improve fitness
- Improve emotional wellbeing



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Treatment of PCOS

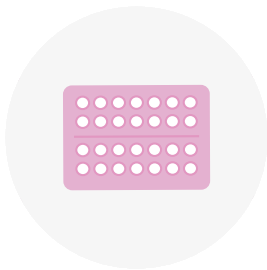
Treatment of irregular periods

An 'irregular' period cycle does not have a regular monthly pattern. The most effective treatment of irregular menstrual cycles is a healthy lifestyle. For some women lifestyle plus medication may be required.

Endometrial cancer

Irregular or infrequent periods (less than four per year) can lead to the build-up of endometrial tissue inside the womb that is linked with endometrial cancer. It is important that if you are not on some form of contraception (that can limit periods but balance endometrial hormones) that you have at least four periods per year. Talk to your doctor if this is not happening as they can prescribe a medication to bring on a period if needed.

Hormonal contraception

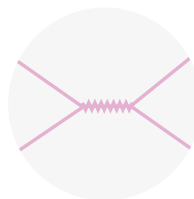


Women with PCOS are commonly prescribed the contraceptive pill to help regulate their periods. One of the actions of the pill is to increase levels of the sex hormone binding globulin (SHBG), which binds to the main androgen testosterone in the blood. This reduces the activity of testosterone and therefore reduces the symptoms related to higher levels of androgens. No one hormonal contraceptive is optimal in PCOS. In general, lower dose preparations are advised, whilst higher dose 35mcg preparations are not recommended firstline.

Treatment of excess hair or hirsutism

Many women with PCOS say that excess body hair (hirsutism) is one of the more difficult symptoms to deal with. This may be because facial or body hair can be seen by others and because excess body hair challenges our idea of how girls and women should look. The good news is that treatments for body hair have improved greatly and are increasingly easy to find and less expensive.

Cosmetic therapy



Waxing, threading, depilatory creams, plucking, laser hair removal and electrolysis can be useful ways to remove hair and reduce hair growth. Laser hair removal is now cheaper and more effective and a good option for many women. A number of laser treatments are required to reduce hair growth and results vary by hair colour, skin type and person. Red hair is more difficult (though not impossible) to remove. White and grey hair cannot be removed with laser treatment as they lack the pigment the laser needs to identify the hair follicles and destroy them. A reputable laser removal professional is important to ensure treatments are deep enough to have a lasting effect on the hair follicle.

Medical therapy

There are a number of medications that may help to reduce excess body hair. Examples include the contraceptive pill, and if the pill is not effective after six months adding in an anti-androgen medication. It is important to be using a form of contraception when taking anti-androgen medications.

PCOS treatment

Early diagnosis and treatment are important for your overall health.

If I have irregular or no periods what can I do?



Aim for a healthy lifestyle and, if needed, a 5 to 10% weight loss (of your overall weight).



Consider taking the oral contraceptive pill as prescribed by your health professional (balances hormone levels, improves cycles, reduces excess face/body hair and acne).



Consider a medication called Metformin if prescribed by your doctor (improves ovulation, menstrual cycles, weight and metabolic features).



When on no contraception, having less than 4 menstrual cycles per year needs medical attention and treatment.

If I have increased body hair what can I do?



Wax



Electrolysis



Thread



Laser hair removal therapy

If commonly used ways to remove hair do not work there are medications that you can try such as; the contraceptive pill (lowers androgen levels) can be used. These medications should be used for about 6 months before changing dose or medication, to be effective. Anti-androgens* can be added at this time if needed. Talk with your health professional about this.

**Please note anti-androgen medications should not be used without adequate contraception.*

If I want to have children, what should I do?



Aim for a healthy lifestyle and reduce weight if needed by 5-10% of total body weight.



Take folate, see your doctor and if needed seek help to cease smoking, reduce alcohol and prepare yourself for a healthy pregnancy.



Consider planning your pregnancy/s prior to age 35yrs to improve pregnancy success rates.



If you have difficulties getting pregnant there is a lot of medical support such as; (first-line) oral ovulation induction agents, (second-line) surgery or injections of gonadotrophins and (third-line) IVF. See Fertility info-graphic.

To reduce my risk of chronic diseases what should I do?



Aim for a healthy lifestyle and reduce weight by 5-10% of total body weight, if needed.



Metformin can help prevent weight gain when combined with a healthy lifestyle and helps balance hormones and reduce risk of developing diabetes.

Fertility

About 70% of women with PCOS experience difficulties getting pregnant. This means that up to 30% of women with PCOS do not have problems getting pregnant. One of the main reasons why women with PCOS experience difficulties getting pregnant is because they may not release a mature egg (ovulation) from the ovary each month.

Ovulation

Ovulation normally occurs once a month when you release an egg (ovum) into a Fallopian tube. The tube takes the egg into the uterus. Before an ovum 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 is released from the ovary into the fallopian tubes. It is important to know that women who are not ovulating regularly still may ovulate occasionally. This is why using a form of contraception is important, if not wanting to get pregnant.

Women with PCOS usually achieve the number of children they desire, but this may take longer and may require medical assistance. For this reason, planning your family earlier than 35 years is good to idea to give you time to seek medical support.

What treatments are available?



The first and most **important** treatment is healthy lifestyle. A healthy lifestyle has been shown to increase chances of becoming pregnant. Also, if you are an unhealthy weight, losing only a few kilograms may help you become pregnant. This is particularly important for women who are an unhealthy weight and not ovulating regularly. For these women losing even a small amount of weight can help ovulation to restart and help achieve pregnancy. In addition, decreased weight can help with having a healthy pregnancy.

Consult your doctor on what your goals should be.



There are a range of oral medications that can be very effective in assisting women to get pregnant in PCOS. The majority of women with PCOS alone as the cause of their infertility, will achieve pregnancy with these oral treatments (if older age or excess weight is present, chances of success can be affected). If these do not work injections or minor ovarian surgery may help.

There are other options available, mainly where there are additional causes of infertility on top of PCOS or where the above options have failed. These include Assisted Reproductive Technology (ART). ART includes treatments such as IVF (in vitro fertilisation). It is important to know that assisted reproductive technology can be expensive and is not always available. Also, having excess unhealthy weight or an age above 35 years decreases the chances of a successful pregnancy when using ART.

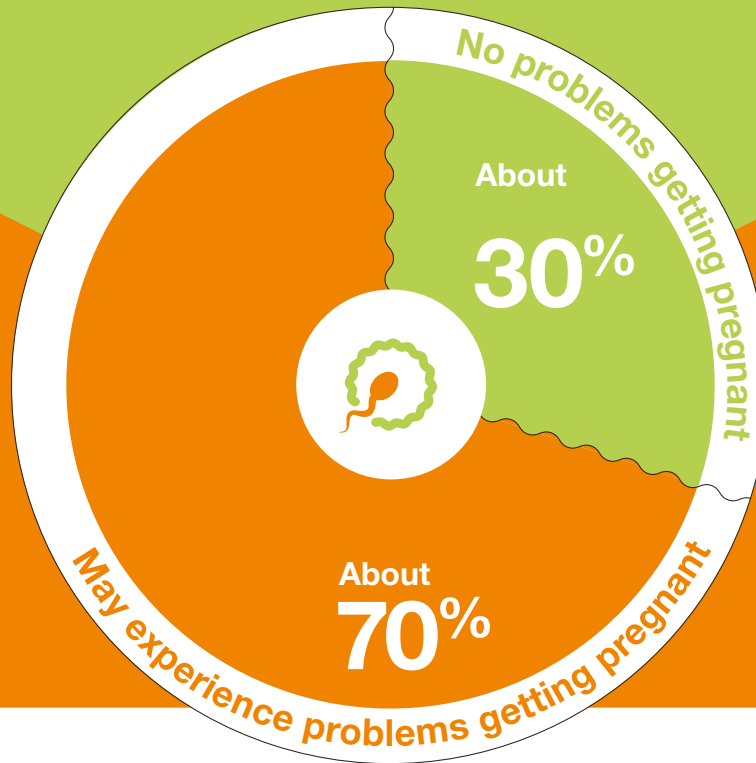
PCOS, fertility and pregnancy

Most women with PCOS achieve their desired family size.
For some of these women medical support may be needed.



Women with PCOS commonly have problems becoming pregnant.

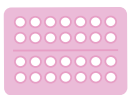
The most common reason is not producing a fully developed egg during the monthly cycle (anovulation).



A healthy and active lifestyle

improves your changes of becoming pregnant.

Improving your chances



Contraception is needed if pregnancy is not desired.



Discuss family planning and pregnancy health with your doctor. Make a plan of action so that you will be in the best health possible when trying to become pregnant.



5%–10%

Aim for a healthy weight to improve your chances of getting pregnant (If you are in the unhealthy weight range, a 5-10% weight loss of your total body weight will improve your chances of becoming pregnant).



Consider planning your family (if you wish to have children) earlier than 35 years if possible.

More helpful information



If you have had no periods or very few periods over the past 3 to 6 months, see your doctor.



If you are not pregnant after trying for 12 months (or if over 35yrs 6 months), see your doctor.



If improving your lifestyle has not achieved a pregnancy then your doctor will discuss treatment options.



The most common treatment is tablets such as letrozole, clomiphene citrate and metformin. Surgery and injections are also options.



Being as healthy as possible when becoming pregnant may reduce your risk of possible problems during pregnancy such as gestational diabetes.



For more information about PCOS and fertility go to:
AskPCOS
Visit yourfertility.org.au or varta.org.au

Conclusion/other resources

PCOS is a common hormonal condition. Fortunately, over the past 10 years a great deal of research has been focused on PCOS. Because of this research, we now understand PCOS better and how to effectively treat symptoms. It is important to monitor and manage your emotional well-being and to work on improving your lifestyle as much as possible. With good social and medical support and education, your quality of life can be greatly improved.

Further PCOS information and resources are available at:

Monash Centre for Health and Research Implementation

www.monash.edu/medicine/sphpm/mchri/pcos

This website provides a comprehensive range of information on PCOS. There are resources for both health professionals and those with PCOS such as; videos from PCOS experts on all aspects of PCOS, PCOS info-graphics providing high quality information in a visual format and, podcasts from those with PCOS and from experts.

The Polycystic Ovary Syndrome Association of Australia Inc (POSAA)

www.facebook.com/PCOSAustralia/

The Association brings together sufferers, their families and friends, and medical professionals interested in supporting the group and PCOS patients.

Verity

www.verity-pcos.org.uk

Verity is a UK based PCOS support network run by women with PCOS.

PCOS Challenge

www.pcoschallenge.org

PCOS Challenge: The National Polycystic Ovary Syndrome Association is the leading USA based nonprofit patient support and advocacy organization globally that is advancing the cause for women and girls with PCOS.

The Victorian Assisted Reproductive Treatment Authority (VARTA)

www.varta.org.au/about-varta

VARTA provides independent information and support for individuals, couples and health professionals on fertility and issues related to assisted reproductive treatment.

Jean Hailes For Women's Health

www.jeanhailes.org.au/health-a-z/pcos

Jean Hailes is a not-for-profit Australian health promotion organisation that provides evidence-based PCOS information.

We also recommend you seek out support groups and other professional societies in your world region if available.

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