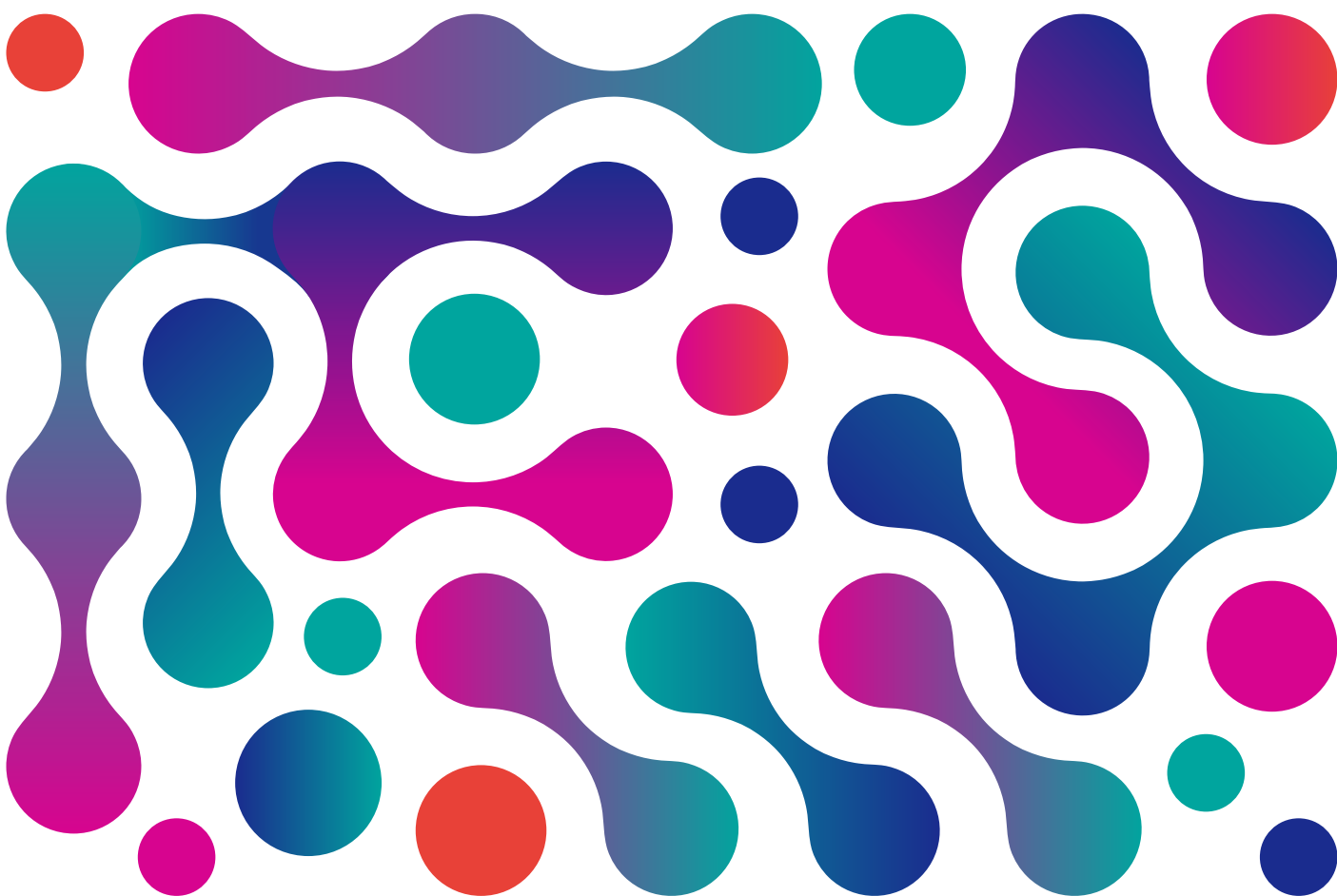


Consumer Booklet

Evidence-based information for women with Polycystic ovary syndrome

2023



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.

This booklet is based on the International evidence-based guideline for the assessment and management of polycystic ovary syndrome 2023. It forms part of an extensive range of resources developed for health professionals and women with polycystic ovary syndrome (PCOS).
To find out more about this program and access PCOS resources please go to: www.mchri.org.au/pcos

Acknowledgements

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- 1 The Australian National Health and Medical Research Council (NHMRC) through the funded Centre for Research Excellence in Women's Health in Reproductive Life (CRE WHiRL) (APP1171592) and Centre for Research Excellence in Polycystic Ovary Syndrome (CRE PCOS) (APP1078444) and the members of this Centre who led and coordinated this international guideline effort
- 2 Our partner organisations which co-funded the guideline:
 - American Society for Reproductive Medicine (ASRM)
 - Endocrine Society (ENDO)
 - European Society of Endocrinology (ESE)
 - European Society of Human Reproduction and Embryology (ESHRE)
- 3 Our collaborating and engaged societies and consumer groups:
 - Androgen Excess and Polycystic Ovary Syndrome Society (AE-PCOS)
 - Asia Pacific Initiative on Reproduction (ASPIRE)
 - Asia Pacific Paediatric Endocrine Society (APPES)
 - Australia and New Zealand Society for Paediatric Endocrinology and Diabetes (ANZSPED)
 - Australian Diabetes Society (ADS)
 - Brazilian Society of Endocrinology and Metabolism (SBEM)
 - British Fertility Society (BFS)
 - Canadian Society of Endocrinology and Metabolism (CSEM)
 - Dietitians Australia (DA)
 - Endocrine Society Australia (ESA)
 - European Society for Paediatric Endocrinology (ESPE)
 - Exercise and Sports Science Australia (ESSA)
 - Fertility Society Australia and New Zealand (FSANZ)
 - International Federation of Fertility Societies (IFFS)
 - International Federation of Gynaecology and Obstetrics (FIGO)
 - International Society of Endocrinology (ISE)
 - Italian Society of Gynaecology and Obstetrics (SIGO)
 - Japanese Society for Paediatric Endocrinology (JSPE)
 - Latin American Society for Paediatric Endocrinology (SLEP)
 - Nordic Federation of Societies of Obstetrics and Gynaecology (NFOG)
 - Paediatric Endocrine Society (PES)
 - PCOS Challenge: The National Polycystic Ovary Syndrome Association
 - PCOS Society of India
 - PCOS Vitality
 - Royal Australasian College of Physicians (RACP)
 - Royal Australian and New Zealand College of Radiologists (RANZCR)
 - Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG)
 - Royal College of Obstetricians and Gynaecologists (RCOG)
 - Society for Endocrinology
 - South African Society of Gynaecology and Obstetrics (SASOG)
 - Verity (PCOS UK)
 - Victorian Assisted Reproductive Technology Association (VARTA)

Other relevant organisations are welcome to partner in guideline translation once approved.



new things to know about PCOS



1

PCOS is a long term condition with wide-ranging features beyond reproductive health.



2

There are knowledge gaps amongst health professionals needing to be addressed by the Guideline resources.



3

Doctors may use AMH levels instead of ultrasound to diagnose PCOS in adults.



4

PCOS carries a strong risk of premature diabetes and heart disease, which needs recognition, screening and prevention.



5

PCOS has a high prevalence of mental health impacts, including depression and anxiety. Stigma related to weight, facial & body hair & severe acne can contribute. Treatment alleviates these.



6

Manage PCOS with healthy lifestyle habits such as being as active as possible and eating healthy food most of the time.



7

Laser & light therapy for reducing unwanted hair caused by PCOS are good options.



8

PCOS is considered a high-risk condition in pregnancy which needs recognition, screening & prevention.



9

Higher weight can affect fertility & pregnancy.



10

There are effective treatments for both the medical & fertility impacts of PCOS.

*Based on changes in the 2023 International Evidence-based Guideline for the assessment & management of polycystic ovary syndrome.



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www.askpcos.org

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Do I have PCOS?

Polycystic Ovary Syndrome (PCOS) is common with no known cure. Knowing how to manage your PCOS is important.

Answer these questions

Do your periods come irregularly, not at all, or sometimes? (not on hormonal contraception)

Do you have excess hair on your face, stomach or back that bothers you? Do you have acne that may be severe?

Do the women in your family have PCOS or symptoms listed below?

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

Symptoms

The symptoms of PCOS vary between women of different ages.



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



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



Low mood, sad for long periods, anxiety, low self-esteem, low motivation



Delays in getting pregnant



Acne, darkened skin patches



Weight gain that is hard to lose

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, or elevated anti-mullerian hormone (AMH) levels — then the appearance of partly formed eggs (fluid filled sacks 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.



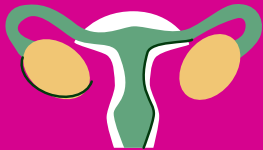
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PCOS, Fertility and Pregnancy

Most women with Polycystic Ovary Syndrome (PCOS) achieve their desired family size. Many of these women may need simple support.



Many women with PCOS have difficulty getting pregnant because their eggs don't fully develop. But the good news is that this issue often responds well to non-invasive medical treatment.

70%

About 70% may experience problems getting pregnant.



A healthy and active lifestyle improves your chances of becoming pregnant.

30%

About 30% may experience no problems getting 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.



If you're in a larger body, **maintaining a stable weight and losing just a few kilos** can significantly improve fertility.



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.



For more information about PCOS and fertility go to: **askpcos.org**



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Emotional Wellbeing and PCOS

Those with Polycystic Ovary Syndrome (PCOS) often experience emotional challenges such as mood changes, distress and low self-esteem.

Awareness

Awareness, early action and a healthy lifestyle are the best ways to reduce this risk.

Monitoring

Monitoring your emotional well-being is important to know when to take action.

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

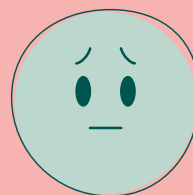
Over the last 2 weeks, how often have you been bothered by the following problems?



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

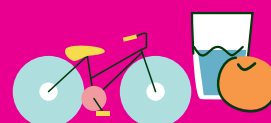
Reduce the risk and severity of these challenges



Educate people close to you about PCOS and the challenges you may face to your emotional wellbeing.



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



Be as active as possible and make healthy food choices most of the time.



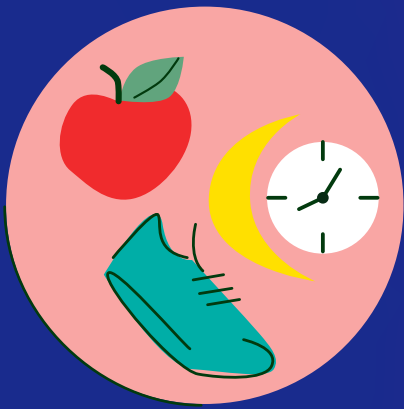
Talk to a health professional about a referral to a mental health specialist.



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Lifestyle and PCOS

Take every opportunity to move.

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

Move at every opportunity



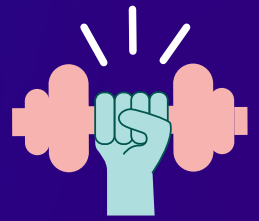
Light



Moderate



Vigorous



Preventing excess weight gain is important in managing PCOS.

Any activity is good activity

Maximum heart rate = 220 minus your age.

How much activity is ideal?

WEIGHT MAINTENANCE

Adult Women
150+ minutes per week moderate activity, **OR** 75+ minutes per week vigorous activity, **OR** Combination of both
INCLUDE weight training 2x per week

WEIGHT LOSS

Adult Women
300+ minutes per week moderate activity, **OR** 150+ minutes per week vigorous activity, **OR** Combination of both
INCLUDE weight training 2x per week

ADOLESCENTS

Adolescents
60+ minutes per day vigorous activity
INCLUDE weight training 3x per week

Healthy prevention of weight gain

- 1 Be kind to yourself. Mood changes can make healthy choices harder.
- 2 Start by focusing on keeping current weight steady, and try out different lifestyle approaches to achieve that.
- 3 Eat a balanced healthy diet as often as you can.
- 4 Reduce sweetened drinks & processed food when possible.

Healthy lifestyle helps to:



Improve how you feel about your body



Make insulin work better & prevent diabetes



Make your periods more regular



Improve energy levels



Improve your fertility



Improve fitness



Improve emotional wellbeing



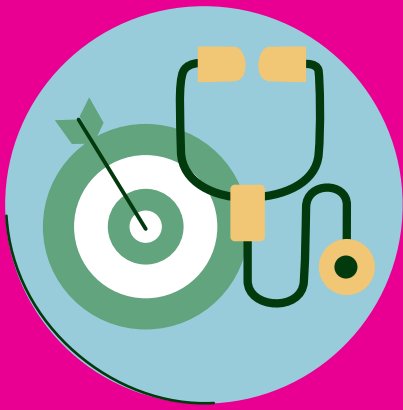
Maintain or reduce weight



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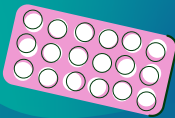
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PCOS Treatment

Early diagnosis and treatment are important for your overall health.

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



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



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



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

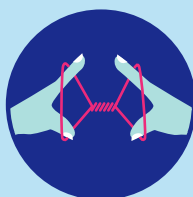
If I have increased body hair what can I do?



Mechanical (laser) & light therapy



Electrolysis



Threading



Waxing

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 Infographic.

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

1 Aim for a healthy lifestyle. For those in a larger body, aim to maintain weight. A small weight reduction can lower chronic disease risk.

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



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