

POLYCYSTIC OVARY SYNDROME (PCOS)

INSIDE:

- The symptoms explained
- Your fertility treatment options
- Coping emotionally with infertility



ABOUT THIS BOOKLET

Merck Healthcare thanks the many individuals, couples and Australian healthcare professionals, including fertility specialists, specialist nurses and psychologists who shared their knowledge and expertise during the production of these booklets.

Important notice: The information provided in this booklet does not replace any of the information or advice provided by a medical practitioner and other members of your healthcare team. Your doctor will determine the best medications and course of action for you based on your requirements and circumstances.

Prescription medicines have benefits and risks. Use all prescribed medicines strictly as directed by your doctor and raise any questions or concerns with them before, during or after using them. If you experience side effects consult your doctor.

Medication availability and funding criteria may differ between Australia and New Zealand.



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INTRODUCTION¹⁻³

If you are reading this booklet you may have been told, or your doctor suspects, that you have polycystic ovary (or ovarian) syndrome (PCOS). This is a common hormonal condition affecting many women.^{1,2} There are many ways to help with the symptoms you might have. The medications and procedures available to help you get pregnant are well-established and generally effective.²

Even so, being diagnosed and coping with the symptoms of PCOS can be emotionally and physically challenging. Symptoms such as acne, excessive hair growth and weight issues can make you feel embarrassed and affect the way you feel about yourself. In addition, some women experience fertility issues and other possible long-term health issues, which may lead to anxiety or even depression.³

This booklet aims to give you information about PCOS – what it is, why you have it, and how to treat it. In the back of the booklet, you will also find contact details for some support organisations.

With the assistance of your healthcare team, PCOS can be effectively managed, allowing you to live a full and healthy life.

There are many ways to help with the symptoms you might have. The medications and procedures available to help you get pregnant are well established and can be effective.²

ABOUT POLYCYSTIC OVARY SYNDROME (PCOS)

What is PCOS?^{1,3,4}

Polycystic ovary (ovarian) syndrome (PCOS) is a common hormonal disorder affecting many women between puberty and menopause. It is called a 'syndrome' because it refers to a number of different symptoms you may experience.^{1,3} It is also known as 'polycystic ovary disease', 'Stein-Leventhal syndrome' or 'hyperandrogen anovulation syndrome'.⁴

The condition is usually diagnosed on identification of at least two of the following:¹

1. Increased androgens (typically masculine hormones, such as testosterone), which may lead to excessive hair growth, or acne.
2. Lack of regular ovulation (irregular menstrual periods or failure to release an egg from the ovary)
3. A characteristic appearance of the ovaries on ultrasound (polycystic ovaries – PCO).



Having polycystic ovaries alone is not enough to make the diagnosis of PCOS. Where required, your doctor will exclude other, rare conditions that may present as PCOS.¹

WHAT'S IN A NAME?¹

The name polycystic ovary syndrome is confusing because not everyone who has the condition has polycystic ovaries. These are ovaries which contain tiny cysts (see page 10 for more information). For many women with PCOS, polycystic ovaries are seen on an ultrasound.

Who gets PCOS?^{1,5}

In Australia and New Zealand, 12–21% of women of reproductive age are diagnosed with PCOS.^{1,5}
In indigenous Australian women, the occurrence of PCOS has been reported to be higher.¹

Why does it occur?^{6,7}

Doctors are not exactly sure what causes PCOS, although it is believed to be linked to both lifestyle factors and genetics – in other words it may run in the family and/or be affected by lifestyle factors such as body weight. Sometimes another family member may have similar symptoms, however PCOS may be inherited from the males in the family where symptoms may not be obvious. Parents and siblings may have some of the metabolic features of PCOS, i.e. insulin resistance (see below).^{6,7}

Many women who have PCOS also have what is known as **insulin resistance**, which occurs when the body struggles to carry out the normal actions of insulin, such as regulating blood glucose levels. High levels of insulin can lead to an increased production of male hormones, such as testosterone, from the ovary, which leads to symptoms of excessive hair growth and acne. Insulin resistance can be caused by genetic factors or lifestyle factors (such as being overweight) and is commonly a combination of both.⁶

There is no known cure for PCOS and it is thought that once you have it, you always will. But you can work together with your doctor to manage your symptoms and change your lifestyle so that you can have a healthy life.¹



THE SYMPTOMS^{2,5,6}

The symptoms and signs are often different for each woman but the following characteristics are common:^{5,6}

- difficulty in becoming pregnant (usually because of a lack of ovulation)
- ultrasound appearance of ovarian cysts (polycystic ovaries)
- periods that are absent (amenorrhoea) or infrequent (oligomenorrhoea)
- excess of male hormones, causing symptoms such as hairiness (hirsutism) or acne
- weight gain and an increase in fat, especially around the abdomen or tummy area
- prediabetes or diabetes
- abnormal levels of blood fats (lipids, such as cholesterol and triglycerides).



We will look in more detail at many of these symptoms on pages 10–13.

One of the most upsetting and frustrating symptoms of PCOS is infertility, however, this doesn't necessarily mean you can't become pregnant. There are many ways to manage infertility, and a large percentage of women conceive after treatment.²

Your menstrual cycle and PCOS⁸

In order to better understand the symptoms of PCOS, you might like to familiarise yourself with the process of ovulation, the menstrual cycle and the role of the various hormones.

The **menstrual cycle** refers to the maturation and release of an egg (ovulation) from an ovary and the preparation of the uterus (womb) to receive and nurture an embryo. A typical cycle takes approximately 28 to 32 days.

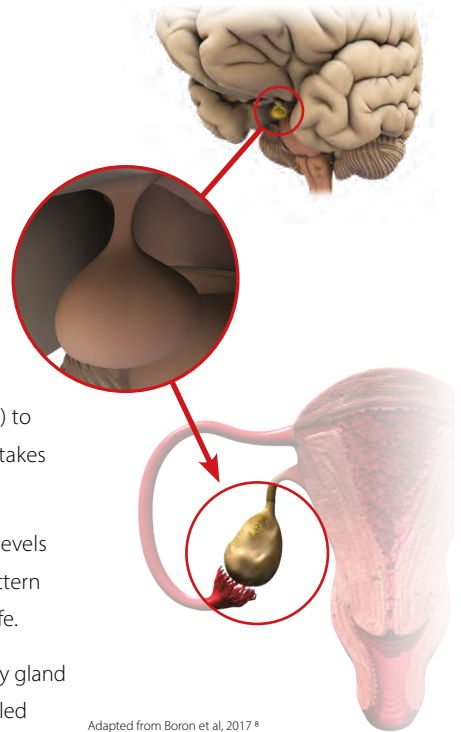
Your menstrual cycle is governed by hormone levels in the body, which rise and fall in a monthly pattern that continues throughout your reproductive life.

When the cycle is running smoothly, the pituitary gland at the base of the brain produces a hormone called follicle stimulating hormone (FSH) to prepare an egg for release. FSH stimulates a fluid-filled sac surrounding the egg to grow into a follicle about 2 cm wide.

When the egg is ready (about two weeks before your period), the pituitary gland produces another hormone called luteinising hormone (LH). This prompts the follicle to release one egg into the fallopian tube in the process known as **ovulation**. Ovulation is the fertile period of a woman's menstrual cycle.

While this is happening, the ovaries are secreting other hormones such as oestrogen and progesterone to thicken the lining (endometrium) of the uterus and prepare it for pregnancy. The ovaries also produce small amounts of androgens (male hormones), such as testosterone, which is largely converted into oestrogen.

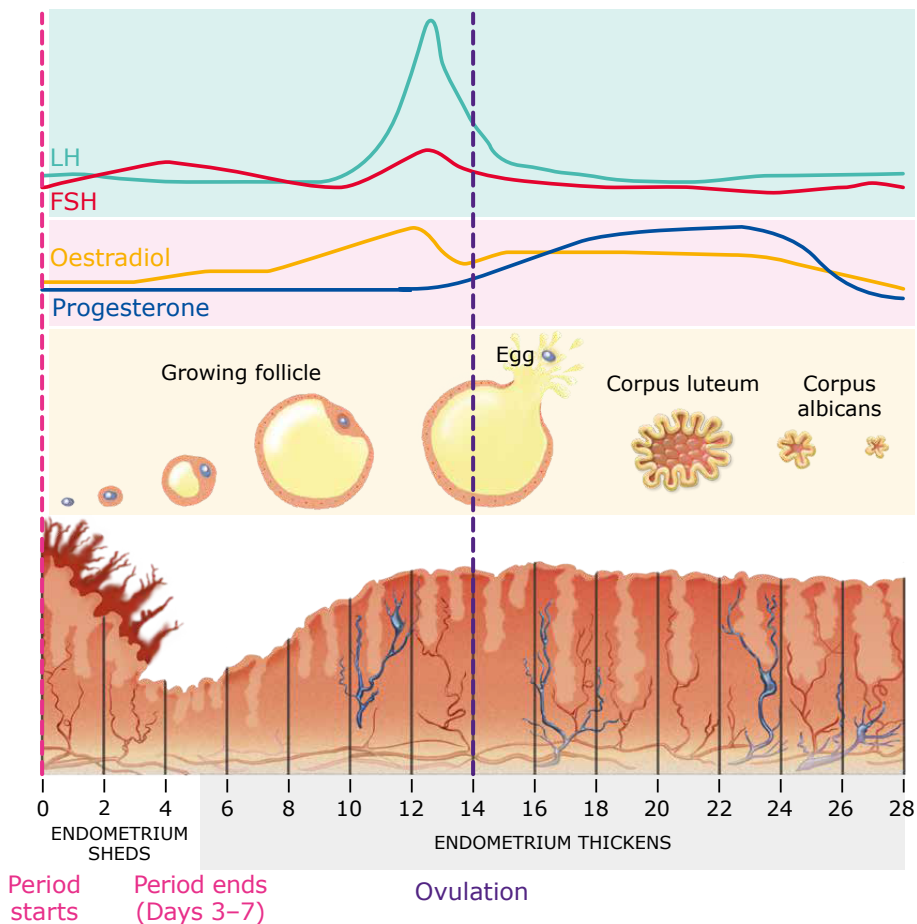
If the egg meets the sperm in the fallopian tube, conception may occur. The fertilised egg is swept through the tube toward the uterus where the embryo – as it is now called – will implant into the lining about six days after ovulation. It begins to produce a hormone called



Adapted from Boron et al, 2017 ⁸

The pituitary gland at the base of the brain releases follicle stimulating hormone (FSH) and luteinising hormone (LH) which are responsible for the development and release of an egg

human chorionic gonadotrophin (hCG), which tells the body it is pregnant. If fertilisation doesn't occur, the levels of oestrogen and progesterone drop again and the lining of the endometrium comes away. This is called your period.



Adapted from Boron et al, 2017 ⁸

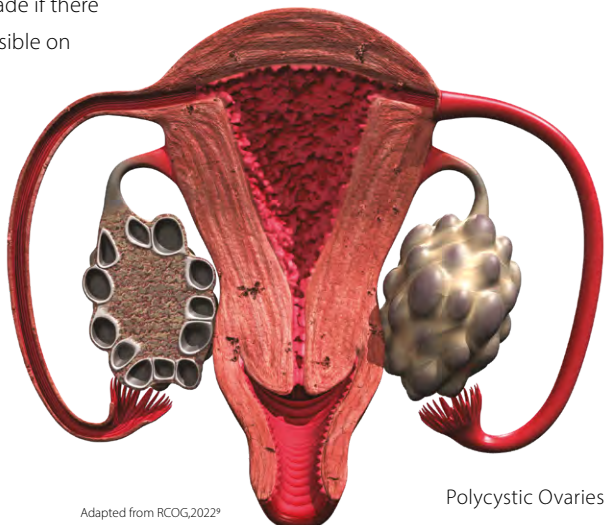
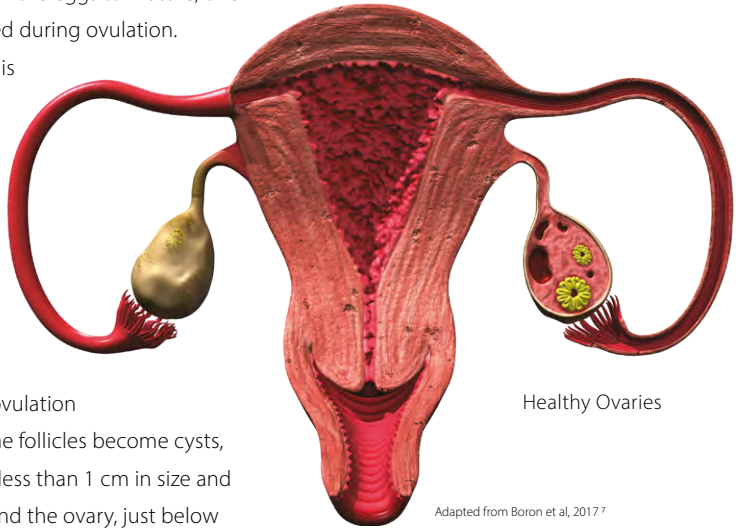
What are polycystic ovaries?^{3,6}

As we have discussed, despite the name, you may or may not have polycystic ovaries as part of the polycystic ovary syndrome. As outlined on the previous page, during each menstrual cycle, follicles allow the eggs to mature, one of which is released during ovulation.

Once this process is completed, the follicles break down and disappear.

With PCOS, these follicles stop growing during this development so ovulation does not occur. The follicles become cysts, which are usually less than 1 cm in size and are arranged around the ovary, just below the surface. On an ultrasound, the diagnosis of polycystic ovaries is made if there are many small follicles visible on one ovary.³

These cysts can lead to a hormonal imbalance because of an increase in the release of testosterone. As mentioned previously, this can result in acne, an increase in facial and body hair and irregular periods.^{3,6}



Irregular periods^{1,6}

When you have PCOS, the usual hormonal activity becomes irregular as ovulation is not occurring in the usual way. The body is given mixed signals and the menstrual cycle is disrupted. Periods can vary widely from woman to woman.^{1,6}

They can range from:

- irregular
- infrequent (oligomenorrhoea)
- heavy
- absent (amenorrhoea).

Difficulty becoming pregnant^{1,2}

This is one of the most frustrating symptoms of PCOS and can cause anxiety, as ovulation may become irregular or even stop.¹ We look at some of the medications and technologies to assist you in becoming pregnant on page 16.

Not all women with PCOS will have fertility problems, and many will have children naturally without any medical treatment.²

Excessive hair growth¹

A high level of androgens (male hormones) might cause you to become hairy (hirsute). Unwanted hair can grow on your face, thighs, back, tummy and nipples.

There are a variety of prescription medications that can help with hairiness. Ask your doctor for more information. However, as these medications may take some time to take effect, you may like to investigate some of the skin therapies available that give immediate results.

Scalp hair loss¹

Losing hair from your head, also known as alopecia, can be another distressing symptom of too much testosterone.

Acne³

Acne may also be caused by higher levels of androgens and can appear on the face, back and elsewhere on the body.

There are various ways to treat acne, including using oral contraceptive (birth control) pills, topical creams and oral antibiotics.

Ask your doctor for further information – they will be able to advise you on the right medication for you.

Insulin resistance³⁻⁵

Many women with PCOS have insulin resistance, meaning that the body cannot easily respond to the normal actions of insulin.⁵ Insulin is a hormone, produced by a gland called the pancreas. Insulin moves glucose from our blood stream into muscle and fat.³

When there are high levels of insulin present in the bloodstream, the body produces more androgens.⁵ These are the same male hormones that can lead to other symptoms of PCOS such as hairiness, irregular periods, acne and difficulty ovulating. Higher levels of insulin can sometimes cause patches of darkened skin on the back of the neck, under the arms and in the groin area (inside upper thighs).³



Insulin resistance can be hereditary.⁴ But it can also be caused by lifestyle factors (such as being overweight), or a combination of the two. The incidence of PCOS increases with weight gain. Insulin resistance can lead to diabetes and other longer-term health implications. If you have a family history of type 2 diabetes, you are more likely to develop this complication.^{3,4}

Reducing insulin levels can be achieved through weight loss, diet and physical activity, and through medications which lower insulin levels (see page 16). This may help to restore normal ovulation, alleviate other symptoms such as acne and excess hair growth, and assist with weight loss.^{3,4}

Many women with PCOS have a decreased response to insulin for which their bodies compensate by overproducing insulin.⁵

Weight problems^{3,4,11}

Women who are overweight are more inclined to develop the symptoms of PCOS than women of a healthier weight range.⁴

Often, even small amounts of weight loss (e.g. less than 5% of body weight) may cause spontaneous ovulation to recur. A healthier lifestyle also promotes positive self-esteem and has other physical and psychological benefits.^{4,11}

Losing weight – while easier said than done – is best achieved by a program of healthy eating and regular exercise (40 minutes, three times a week). Ask your doctor for advice about the best type of eating plan for you, e.g. lowering your intake of carbohydrates, sugar and fatty foods and choosing foods with a lower GI (glycaemic index) may be a good starting point.³ You may also like to consult a dietitian – ask your doctor or see the Dietitians Association details in the back of this booklet.



WEIGHT GAIN: SYMPTOM OR CAUSE?^{4,6}

For some people, weight gain might be a symptom of the condition, rather than the cause. One reason for gaining weight in the first place might be due to distress over having trouble becoming pregnant. Another reason may be due to feelings related to a poor body image, possibly related to skin conditions such as hairiness or acne. Insulin resistance is another possible cause of weight gain. Losing weight may help, but it's not always easy when you are feeling emotional pressure. Adopting a healthier lifestyle can improve insulin levels, self-esteem and reduce other symptoms overall. It can also stimulate ovulation.^{4,6}

Long-term effects^{4,9}

Women experiencing the symptoms of PCOS should talk to their doctor about how to minimise any long-term effects. You may be at risk of developing the following:

Diabetes – Since many women with PCOS are insulin resistant, this means that many have an increased risk of developing pre-diabetes or type 2 diabetes.⁴

Complications in pregnancy, i.e. gestational diabetes – Women with PCOS who become pregnant are more likely to develop diabetes during pregnancy.⁹

Cardiovascular disease – There is a potential for an elevated risk of heart disease and high blood pressure, which is further increased if women are overweight.⁴

Metabolic syndrome – This cluster of illnesses can occur with PCOS. It includes impaired glucose intolerance, which is closely related to type 2 diabetes. It also includes obesity and high blood cholesterol.⁴

Endometrial cancer – This cancer is three times more common in women with PCOS. When women experience few or no periods, the endometrium or lining of the uterus can thicken and develop cancerous cells.⁴

What can help?

Your body image and self-esteem^{3,6}

For some people, dealing with the challenges of PCOS and its accompanying symptoms, including acne, weight gain and hairiness, can often damage self-esteem. This can lead to concern over body image, as well as anxiety, stress, loneliness and even depression.

The following hints may be helpful:

- banish negative self-talk. Don't say anything to yourself that you wouldn't say to a good friend. If you find yourself thinking self-critical thoughts, stop yourself and talk back to them with some new positive messages.
- prioritise looking after yourself by doing things you like. Plan fun and relaxing things and set goals for healthy eating and regular exercise. You might like to find a new interest, such as joining a book club.
- seek professional support. If you find that you have a lot of difficulty seeing yourself realistically, seek help from a trained counsellor or psychologist. Ask your doctor for advice or see the contact details at the back of this booklet.

DIAGNOSING PCOS^{1,3-5,10}

There is no specific test for PCOS but your doctor will consider your symptoms and usually complete a physical examination, blood tests and a transvaginal ultrasound. If you are trying to become pregnant, you may be referred to a gynaecologist or a fertility clinic.^{1,5}

Physical examination: Your doctor will ask you numerous questions about your menstrual cycle, symptoms, weight and examine you for physical signs of PCOS, e.g. acne, excess hair growth and darkened skin.^{1,3}

Blood tests: Your blood may be tested for high cholesterol, blood sugar levels (i.e. insulin resistance) and for changes in LH (luteinising hormone) or FSH (follicle stimulating hormone).^{3,5}

Transvaginal ultrasound: A long slender probe is inserted into the vagina to determine the presence of ovarian cysts or enlarged ovaries and also to examine the reproductive organs for any irregularities. If you would prefer not to have a vaginal scan, your doctor may conduct an ultrasound of your abdomen – done externally while you have a full bladder.¹⁰



TREATING PCOS¹⁻³

Treatment of PCOS can either focus on treating the symptoms, or treating the cause of the symptoms.¹ We have discussed some of the treatments for the symptoms on previous pages and these are summarised in the chart below. Your doctor can help you decide on the best treatment for you.

Treatment summary chart¹⁻³

Symptoms	Treatment
Obesity, weight gain	Weight loss options include: <ul style="list-style-type: none">• changes to diet• exercise• medications*
Hirsutism (hairiness)	<ul style="list-style-type: none">• cosmetic treatments, i.e. waxing, bleaching, laser, electrolysis• weight loss• medications*
Acne	<ul style="list-style-type: none">• topical creams• medications*, i.e. oral contraceptive pill, anti-androgens , retinoids
Insulin resistance	<ul style="list-style-type: none">• weight loss
Diabetes	<ul style="list-style-type: none">• changes to diet• exercise• medications*
Irregular and/or heavy periods	<ul style="list-style-type: none">• weight loss• medications*, i.e. oral contraceptive pill (see page 18)
Infertility	<ul style="list-style-type: none">• weight loss• medications* to improve ovulation

*Your doctor will determine the best medications and course of action for you based on your requirements and circumstances.

Treating insulin resistance⁴

There are a number of medications that will improve insulin sensitivity. If you are diagnosed with insulin resistance, your doctor will advise you what medication to use and when to use it.⁴

Improving fertility^{3,12}

We have already discussed the importance of weight loss in treating PCOS and how to treat the individual symptoms (see table on previous page). On the following pages, we will look at some of the other effective medications and methods available to help you become pregnant.

If you are having trouble becoming pregnant, PCOS may interfere with your menstrual cycle and ovulation.³ If you have regular periods and ovulate, it is unlikely that PCOS is preventing you from becoming pregnant, even if you have polycystic ovaries.¹²



Hormonal therapies^{1,3,8}

If testing indicates that ovulation is irregular or absent, medication that helps you produce eggs will probably be the starting point for treatment. Typically, a doctor will begin what is known as 'ovulation induction' (the use of medicine to promote ovulation). It works best for those women whose ovaries are capable of functioning but who need a little assistance.^{1,3}

In a normal cycle, the hypothalamus (part of the brain that controls a large number of bodily functions) releases a hormone called gonadotrophin-releasing hormone (GnRH) at the beginning of your menstrual cycle. If too little or too much is released, normal follicle development will not take place and ovulation will not occur. Medication can stimulate the release of GnRH, which in turn causes the pituitary gland to release more FSH and LH. These two hormones promote growth of the fluid-filled sacs (follicles) in the ovary, containing the eggs.⁸

Laparoscopic ovarian surgery^{1,11}

If hormonal treatments have not been successful, a laparoscopic ovarian diathermy operation may be recommended by your doctor. It is a small procedure, done under a general anaesthetic. A laparoscopic needle is inserted into the pelvic area to view the ovaries, fallopian tubes and uterus. A series of small holes or burns is made into each ovary. This procedure can lead to changes in hormone levels and may temporarily restore ovulation.

Assisted reproductive technology (ART)¹¹

Assisted reproductive technology (ART) is a general term referring to methods used to unite sperm and eggs by artificial or partially artificial means. The most common ART procedures include ***in vitro* fertilisation (IVF)**, **intrauterine insemination (IUI)**, and **intra-cytoplasmic sperm injection (ICSI)**. Please see the summary table on the next page, which explains some of the more common methods available.

ART at a glance^{11,13}

Procedure	Description	When is it used?
IUI (intrauterine insemination – also known as artificial insemination)	Large numbers of healthy sperm are injected at the entrance of the cervix or high in the uterus, bypassing the cervix and giving direct access to the fallopian tubes.	Existence of sperm antibodies in a woman's cervical mucus. Mild male infertility due to a moderately low sperm count or low number of healthy sperm (see also ICSI). Unexplained infertility.
ICSI (intra-cytoplasmic sperm injection)	A technique in which a single sperm is selected and injected into an egg.	Male infertility when very few normal sperm are available. Fertilising ability of sperm is dramatically reduced.
IVF (In vitro fertilisation)	Hormone therapy with gonadotrophins is given to stimulate the ovaries to produce several mature eggs. Eggs are collected and fertilised in vitro (outside of the body) with either the partner's or donor sperm. If fertilisation occurs within 24 to 28 hours, one or more embryo(s) are placed in the uterus.	Treatment of infertility due to fallopian tube obstructions, PCOS and endometriosis, among other conditions. Male infertility due to sperm abnormalities which prevent fertilisation. Some cases of unexplained infertility.

Booklets from the *Pathways to Parenthood* series providing more detailed information on **ART** and **IVF** are available at www.fertilityportal.com.au/merck

The risk of multiple pregnancies^{2,13}

The ovaries are highly sensitive so selecting the right treatment for you is important. Fertility drugs can cause more than one follicle to develop and this is why your body will be monitored closely through blood tests and ultrasounds during fertility treatment. If more than one follicle develops and there is a risk of multiple pregnancies (e.g. twins), you may be advised to avoid intercourse in this case to prevent multiple pregnancies and related complications. The clinic or healthcare professional will also advise against proceeding with the hCG injection. For those having trouble becoming pregnant, being pregnant with twins may be seen as a blessing, but complications, such as the health risks involved with premature births, are much more common in twin than singleton pregnancies.^{2,13}

Ovarian hyperstimulation syndrome¹³

Ovarian hyperstimulation syndrome (OHSS) is a potentially life-threatening medical condition which may occur when your ovaries have been overly stimulated by various fertility medications. The ovaries may increase in size and produce large amounts of fluid. It is characterised by pain and bloating in your abdomen and if severe can cause breathing or problems with urination.¹³ Contact a member of your healthcare team immediately if you believe you have any of these symptoms.

COPING EMOTIONALLY WITH INFERTILITY¹³

We have already discussed how seriously PCOS can affect your confidence and body image (see page 15). In addition, if you are considering treatment for your PCOS in order to become pregnant, you will have to cope with the emotions and frustrations of undergoing fertility treatment.



The inability to conceive a child touches our deepest self. Women who are unable to become pregnant can often feel inferior, guilty and have problems with their self-image. Men often feel that their virility and manhood is placed in doubt.

Many couples who have experienced infertility treatment describe it as an 'emotional roller coaster'. With each monthly cycle and course of treatment, hopes rise of finally getting pregnant. During the ART process, the two-week wait to assess possible pregnancy after the embryo has been transferred to the uterus can be extremely difficult and traumatic. If the results are negative, the emotional effects can be very difficult to handle.

Talking about your feelings, especially with your partner, is vital to coping with the emotions associated with fertility treatment. If ever love and mutual understanding are called upon, it is in moments such as these. Communicating openly with friends and family can create a stronger sense of support in dealing with the psychological and emotional components of infertility.

It can also be helpful to talk to other couples who have gone through similar experiences and understand what you are feeling. Ask your infertility specialist for the contact details of a support group near you or contact one of the organisations listed in the back of this booklet.

Finally, you can soften the emotional impact of fertility treatment by not expecting instant success. You will need to be patient and develop some coping methods for the frustrations and challenges ahead.

Refer to the *Pathways to Parenthood* booklet on the stress of infertility for more information.

GLOSSARY

Amenorrhoea: Absence of periods (menstruation).

Androgens: Male hormones (such as testosterone). All women produce a small amount of male hormones in tissues, including the ovaries. These male hormones are converted into oestrogens, which are the main female hormones.

Assisted reproductive technology (ART): A general term referring to methods used to achieve pregnancy by artificial or partially artificial means.

Embryo: Term used to describe a fertilised egg after it starts to develop.

Fallopian tubes: A pair of tubes that link the ovaries to the uterus. It is also where fertilisation of the egg with the sperm occurs.

Follicle: Fluid-filled sac in the ovary that holds, nurtures and during ovulation releases the developing egg.

Follicle stimulating hormone (FSH): A hormone that is made by the pituitary gland in the brain, which stimulates the ovary to develop a follicle for ovulation in women and stimulates the production of sperm in the testicles of the male.

Menstrual cycle: A woman's monthly process when the body releases an egg, prepares itself for fertilisation of the egg by sperm and creates an environment in the uterus in which the embryo can implant.

Oestrogen: A female hormone produced mainly by the ovaries from the onset of puberty until menopause. Involved in ovulation and the menstrual cycle.

Oligomenorrhoea: Infrequent periods.

Ovulation: Release of a mature egg from an ovarian follicle usually at about midpoint in the menstrual cycle.

Ovulation induction or stimulation: The use of hormonal medication to promote ovulation.

Ovaries: The two small almond shaped organs that contain a woman's eggs.

Oocyte: The technical term for an unfertilised egg.

Polycystic ovary (or ovarian) syndrome (PCOS): The development of multiple cysts in the ovaries due to arrested follicle growth. This may be related to an imbalance in the amount of LH and FSH released during the ovulatory cycle, leading to irregular menstrual cycles and raised androgen levels.

Uterus: Pear shaped organ (the womb) that provides a safe environment for implantation of the fertilised egg.

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Looking for more information?

Other booklets in the *Pathways to Parenthood* series are available at www.fertilityportal.com.au/merck:

- Your step by step guide to treating infertility
- Overcoming male infertility
- Female infertility & assisted reproductive technology (ART)
- Endometriosis
- Ovulation induction (OI)
- Intrauterine insemination (IUI)
- *In vitro* fertilisation (IVF) & intra-cytoplasmic sperm injection (ICSI)
- Managing the stress of infertility
- Creating families for same-sex couples