

NIMAAYA



POLYCYSTIC OVARY SYNDROME (PCOS)



About this booklet

This series of booklets has been developed and written with the support of leading fertility clinics across Australia, and Access Australia — a national organization that provides numerous services for people having difficulty conceiving. We also acknowledge the many people who spoke openly about their own experiences with assisted conception in order to help others experiencing a similar journey. Merck Serono 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 conditions.

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

Full information regarding the medicines listed in this booklet, including how they are taken and side effects, is available from the Consumer Medicine Information (CMI) sheets. These can be found at the TGA website (www.tga.gov.au) for Australian residents and the medsafe website (www.medsafe.govt.nz) for New Zealand residents.

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

Content

1. Content
2. Introduction
3. About Polycystic Ovary Syndrome (PCOS)
 - What is PCOS?
 - Who gets PCOS?
 - Why does it occur?
4. The symptoms
 - Your Menstrual Cycle and PCOS
 - What are Polycystic Ovaries?
 - Irregular periods
 - Difficulty becoming pregnant
 - Excessive hair growth
 - Scalp hair loss
 - Acne
 - Insulin resistance
5. Diagnosing PCOS
6. Treating PCOS
 - Treating Insulin Resistance
 - Improving Fertility
7. ART at a glance
8. Coping emotionally with Infertility

Introduction

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. There are many ways to help with the symptoms you might have, and the medications and procedures available to assist you in becoming pregnant are well- established and effective.

Even so, being diagnosed and coping with the symptoms of PCOS can be both emotionally and physically challenging. Symptoms such as acne, excessive hair growth and weight issues can make you feel embarrassed and affect your self-esteem. There are also fertility issues and other possible long-term health implications, which may lead to anxiety or depression.

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 treated and managed, allowing you to live a full and healthy life.

There are many ways to help with the symptoms you might have, and the medications and procedures available to assist you in becoming pregnant are well-established and effective.

About Polycystic Ovary Syndrome (PCOS)

What is PCOS?

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 symptoms experienced at the same time. It is also known as 'polycystic ovary disease', 'stein-leventhal syndrome' or 'Hyperandrogen Anovulation Syndrome'.

The condition is usually diagnosed based on the following factors:

- Increased androgens (male hormones, such as testosterone), as shown by excess hair growth, acne or raised blood testosterone levels
- Lack of regular ovulation (irregular menstrual periods or failure to release an egg from the ovary)
- A characteristic appearance of the ovaries on ultrasound (Polycystic Ovaries – PCO).



Usually the diagnosis of pcos requires the presence of at least two polycystic ovaries. 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.

What's in a name?

The name polycystic ovary syndrome is confusing because not everyone who has the condition has polycystic ovaries. These are ovaries which contain about 12 or more tiny cysts (see page 8 for more information). For many women with pcos, polycystic ovaries are seen on an ultrasound.

Many women have Polycystic Ovaries but none of the other symptoms of PCOS and are able to ovulate normally.

Who gets PCOS?

In Australia 12–21% of women of reproductive age are diagnosed with PCOS. In indigenous Australian women, the occurrence of PCOS has been reported to be higher. It is thought that PCOS will increase in line with the rising rate of obesity in Australia.

Why does it occur?

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 runs in the family. Sometimes another family member may have similar symptoms, however PCOS may be inherited from the male side where symptoms may not be obvious. Parents and siblings may have some of the metabolic features of PCOS, i.e. Insulin resistance (see below).

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 also increase the production of male hormones, including testosterone, from the ovary, which contributes to such symptoms as excessive hair growth and acne. Insulin resistance can be caused by genetic factors or lifestyle factors (such as being overweight) or it can be due to a combination of both.²

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 treat the various symptoms and manage your lifestyle so that you can have a healthy life.



The symptoms

The symptoms and signs are often different for each woman but the following characteristics are common:

- Difficulty in becoming pregnant (because of lack of ovulation)
- Ultrasound appearance of ovarian cysts (Polycystic Ovaries)
- Periods that are absent (amenorrhoea) or infrequent (Oligomenorrhoea)
- Excess 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 8–11.



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

Your Menstrual Cycle and PCOS

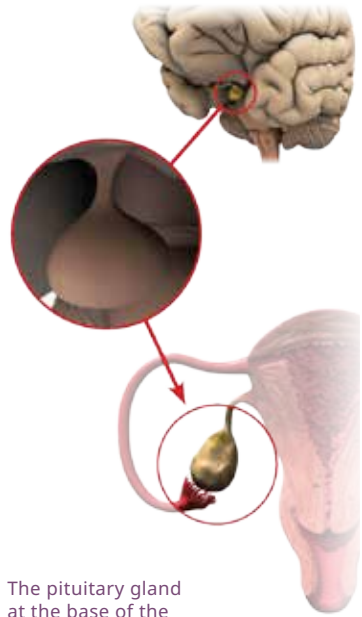
In order to better understand the symptoms of pcos, you might like to familiarise yourself with the process of ovulation, the menstrual cycle and the role of the various hormones.

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 24 to 35 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.

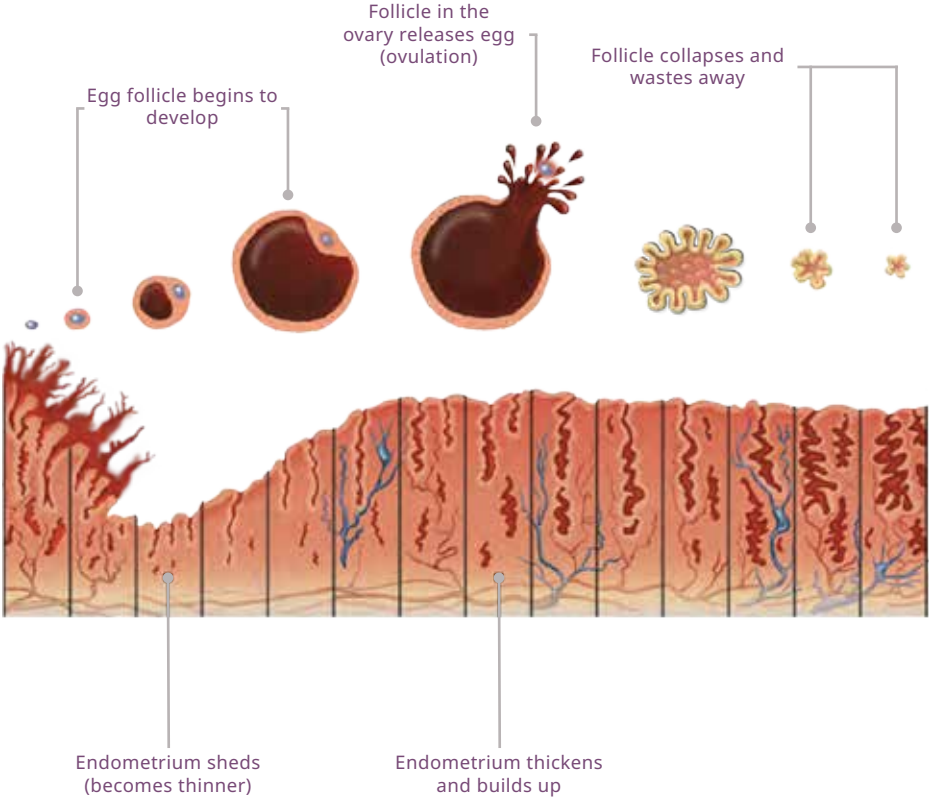
When the egg is ready (about two Weeks before your period), the pituitary gland produces another, the pituitary gland at the base of the brain releases follicle stimulating hormone (FSH) and luteinising hormone (LH) which are responsible for the development and release of an egg hormone called luteinising 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 converted into oestrogen.



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.

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 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.



Born with a lifetime's supply of eggs

Females are born with about 400,000 immature eggs (Oocytes) stored in their ovaries. Each cycle, one of your ovaries selects between 10 and 20 eggs to become possible candidates for release. However, generally only one egg is released each cycle.

What are Polycystic Ovaries?

As we have discussed, despite the name, you may or may not have polycystic ovaries as part of having polycystic ovary syndrome. As outlined on the previous page, during each menstrual cycle, follicles develop to allow maturation of eggs, one of which is released during ovulation. Once this process is completed, the follicles break down and disappear. With PCOS, these follicles stop growing at about half way to maturity and ovulation does not proceed. The follicles become cysts, which are usually less than 1cm in size and are arranged around the ovary, just below the surface. On an ultrasound, the diagnosis of polycystic ovaries is confirmed if there are more than 12 follicles visible on one ovary.

These cysts 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.



Healthy Ovaries



Polycystic Ovaries

Irregular periods

When you have pcOs, hormone activity becomes irregular because ovulation is not occurring in an expected way. The body is given mixed signals and the menstrual cycle is disrupted. Periods can vary widely from woman to woman. They can range from:

- Irregular
- Infrequent (Oligomenorrhoea)
- Heavy
- Absent (Amenorrhoea).

Some women with few or absent periods may build up a very thick lining in the uterus, and this may increase the risk of abnormal cells that, as a woman ages, can develop into cancerous cells.

Difficulty becoming pregnant

This is one of the most frustrating symptoms of pcOs and can cause the most anxiety. The high levels of androgens can cause ovulation to become irregular or even to stop. We look at some of the medications and technologies to assist you in becoming pregnant on page 14.

Not all women with pcOs will have fertility problems, and some will have children naturally without any medical treatment.

Excessive hair growth

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 beauty therapies available that give immediate results.

The symptoms (cont.)

Scalp hair loss

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

Acne

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

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

Your doctor or a dermatologist may prescribe certain stronger medications including anti-androgens—cyproterone acetate, spironolactone—or a retinoid isotretinoin. These types of medications need to be taken in conjunction with effective contraception as they may harm a foetus.

Insulin resistance

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

When there are high levels of insulin present in the bloodstream, the body produces more androgens. These are the same male hormones that can lead to other symptoms of pcos such as weight gain, 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).

Insulin resistance can be hereditary. 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.

Reducing insulin levels can be achieved through weight loss, diet and physical activity, and through medications which lower insulin levels (see page 14). This may help to restore normal ovulation, alleviate other symptoms such as acne and excess hair growth, and assist with weight loss.

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

Weight problems

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

Often 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.

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. You may also like to consult a dietitian—ask your doctor or see the dietitians association details in the back of this booklet.

Weight loss: Symptom or cause ?

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 because of distress over having trouble becoming pregnant. Another reason might be poor body image due to the other symptoms such as hairiness or acne. Insulin resistance is another 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.

Long term effects

Women experiencing symptoms 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.

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

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.

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.

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.

What can help?

Your body image and self-esteem

For some people dealing with the challenges of pcos and its accompanying symptoms, including acne, weight gain and hairiness, can often damage self-esteem and 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.
- Start treating yourself as a worthwhile person. 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.
- Get help. 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

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.

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.

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).

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.

Symptoms

Treatment

Obesity, Weight Gain

Weight loss options include:

- Changes to diet
- Exercise
- Medications*

Hirsutism (hairiness)

- Medications*
- Cosmetic treatments, i.e. waxing, bleaching, laser, electrolysis
- Weight loss

Acne

- Topical creams
- Medications*, i.e. oral contraceptive pill, anti-androgens, retinoids

Insulin resistance diabetes

- Weight loss
- Changes to diet
- Exercise
- Medications*

Infertility caused by irregular periods and ovulation

- Weight loss
- Medications*, oral contraceptive pill (see page 16)

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

Treating PCOS

Treatment of PCOS can either focus on treating the symptoms or treating the cause of the symptoms. We have discussed some of the treatments for the symptoms on previous pages and these are summarised in the chart below.

Treating Insulin Resistance

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

Improving Fertility

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 could be interfering with your menstrual cycle and ovulation. If you have regular periods and ovulate, it is unlikely that pcos is preventing you from becoming pregnant, even if you have polycystic ovaries.

Hormonal therapies

Oral contraceptive pill

The oral contraceptive or birth control pill ('the pill') can help regulate menstrual periods and reduce menstrual cramps. It contains oestrogen and progesterone which take over the body's normal hormonal control of the menstrual cycle and ovulation. It also helps to reduce the testosterone level, which reduces such symptoms as hairiness and acne.

How is it taken?: There is a wide range of oral contraceptive pills with differing doses of oestrogen and progesterone. Your doctor will determine the right one for you.

Clomiphene citrate

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) with clomiphene citrate. It works best for those women whose ovaries are capable of functioning but who need a little assistance.

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. Clomiphene citrate stimulates 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) containing the eggs.

Your doctor will advise you on how many courses you should take. If Clomiphene Citrate has not worked for you, medications containing FSH and LH, i.e. Gonadotrophins (see below) may be prescribed.

Clomiphene citrate and multiple pregnancies

According to the American society for reproductive medicine, women who conceive with clomiphene have approximately a 10% chance of having twins. It is rare (<1%) to have more than twins but triplets and higher multiple pregnancies may occur. Careful monitoring is therefore recommended during treatment with clomiphene citrate.

Be aware of ovarian hyper stimulation syndrome

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 difficulties or problems with urination. Contact a member of your healthcare team immediately if you believe you have any of these symptoms.

Gonadotrophins

If Clomiphene Citrate does not work, the next stage of treatment is usually to start administering a category of medication called Gonadotrophins injectable forms of FSH and HCG. Where Clomiphene Citrate acts to stimulate the release of GNRH, Gonadotrophins act directly on the ovary, promoting follicular development.

The injection of high levels of FSH (and sometimes also LH) stimulates your ovaries to develop multiple follicles and eggs. Ideally no more than one to two eggs should develop to maturity—more than this may lead to a high risk of multiple birth. The growth of your eggs will be carefully monitored using ultrasound.

There are a variety of different treatment medications that fall under the category of gonadotrophins.

Follicle stimulating hormone (FSH) stimulates development of the fluid-filled sacs containing the eggs.

Luteinising hormone (LH) is sometimes used together with FSH to stimulate the development of follicles.

Human chorionic gonadotrophin (HCG) causes the final maturation and release of an egg. While taking hormonal medications, you will be closely monitored, so be prepared for frequent office visits, regular blood tests and pelvic ultrasounds.

Laparoscopic ovarian surgery

When 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 drill-holes or burns is made into each ovary, releasing male hormones stored in the cysts and temporarily restoring ovulation.

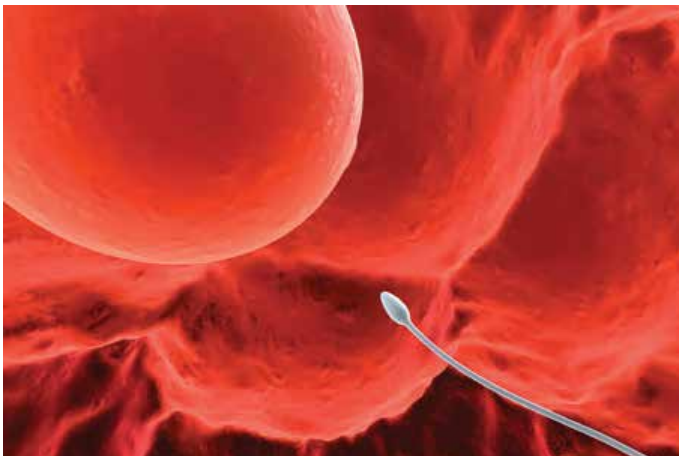
Assisted Reproductive Technology (ART)

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.

In Vitro Fertilisation (IVF)

In Vitro Fertilisation (IVF) was the first art procedure and is still one of the most commonly used. IVF has the same pregnancy success rate for women with PCOS as for those without.

During an IVF cycle, eggs and sperm are collected and placed together in a laboratory dish to fertilise. Hormonal medications are usually used to help stimulate the development of as many eggs as possible (as discussed on pages 14–17). If the eggs are successfully fertilised in the lab, they are transferred into the woman's uterus through a soft tube via the vagina. Ideally, the fertilised egg will implant and develop, just as in a routine pregnancy.



ART at a glance

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. Male infertility due to moderately low sperm count or low number of healthy sperm (see also ICSI). Unexplained infertility.
ICSI (Intracytoplasmic 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 retrieved 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. Male infertility due to sperm abnormalities which prevent fertilisation. Some cases of unexplained infertility.

Coping emotionally with Infertility

We have already discussed how seriously PCOS can affect your confidence and body image (see page 13). 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 an IVF process, the two-week wait after the fertilised egg has been transferred to the uterus can be extremely difficult and traumatic. And 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. However, it is helpful to bear in mind that many couples who undergo treatment do eventually have the baby they want so badly.

Looking for more information?

other booklets in the Pathways to Parenthood series are available at: www.nimaaya.com

- Endometriosis
- Overcoming male Infertility
- Female infertility & assisted reproductive technology (Art)
- Your step by step guide to treating Infertility
- Polycystic ovary syndrome (PCOS)
- Ovulation Induction (OI)
- Intra Uterine Insemination (IUI)
- In Vitro fertilisation (IVF) & Intra-cytoplasmic sperm injection (iCsi)
- Managing the stress of Infertility
- Why investigate for infertility
- Laser assisted Hatching
- Male Infertility
- Oocyte Vitrification
- Semen Analysis
- Why Investigate for Infertility

