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AURORA WOMEN'S HEALTH

POLYCYSTIC OVARIAN SYNDROME (PCOS)

Patient information to assist informed consent

Polycystic ovarian syndrome (PCOS) is a hormonal disorder with a wide range of symptoms and signs. PCOS occurs in up to 10 of every 100 women of child-bearing age in Australia and New Zealand. PCOS can start around puberty.

As a gynaecologic disorder, PCOS is a leading cause of impaired ovulation, infertility and excessive production of male hormones (androgens). PCOS can have a major effect on the reproductive, metabolic and cardiovascular health of affected women. A woman's emotional wellbeing and mental health can also be affected.

Doctors are not certain about its causes, and they regard PCOS as treatable but not curable. Early diagnosis, careful treatment planning and information are important to help protect women and girls with PCOS from adverse long-term effects and to assist with healthier living.

The aims of treatment are to restore regular menstruation, improve metabolic function, achieve ovulation and facilitate pregnancy, as desired.

PCOS may cause symptoms and signs such as:

- disruptions of the menstrual cycle, including irregular, heavy or absent periods or spotting between periods
- slightly enlarged or "lumpy" ovaries with many small follicles in them, known as "polycystic" ovaries; these follicles are fluid-filled cavities that surround immature egg cells (these cysts do not cause pain, do not burst and do not usually require surgery)
- difficulty in becoming pregnant due to irregular ovulation
- pregnancy problems such as gestational diabetes, pregnancy-related high blood pressure, or premature labour
- excessive hair growth (hirsutism), which may occur on the face, chest, back, lower abdomen or thighs
- oily skin, acne and pimples
- obesity and difficulty losing weight
- sleep apnoea (brief periods of not breathing while asleep, which is linked to being overweight)
- high blood levels of cholesterol and fats
- fatty liver, which may be linked to liver disease
- mood disorders, which may need treatment in some patients
- insulin resistance, which occurs in seven out of 10 women with PCOS. Insulin is a hormone made by the pancreas that helps the cells of the body to use sugar. High levels of insulin in PCOS patients make weight loss more difficult and can stop ovulation.

Long-term issues may include:

- depression, anxiety and body-image problems
- type 2 (adult-onset) diabetes
- cardiovascular disease and high blood pressure

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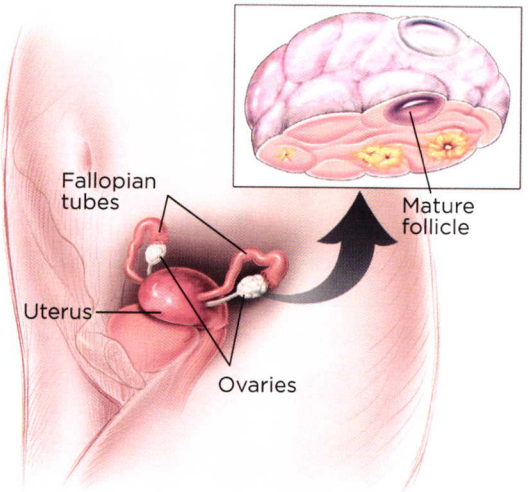
IMPORTANT: Fill in all details on the sticker below.

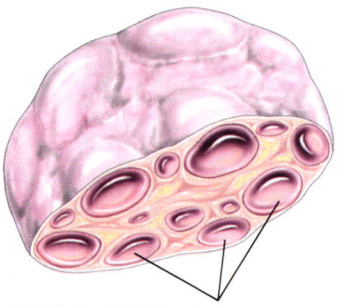
Dear Doctor: When you discuss this pamphlet with your patient, remove the sticker and put it on the patient's medical history or card. This will remind you and the patient that this pamphlet has been provided. Some doctors ask their patients to sign the sticker to confirm receipt of the pamphlet.

NORMAL OVARY



An ovary contains immature eggs, each housed within a tiny sac (follicle). One egg reaches maturity per month and bursts from its follicle (ovulation) to travel down the fallopian tube.

CROSS SECTION OF A POLYCYSTIC OVARY



Multiple follicles (or egg sacs)

TALK TO YOUR DOCTOR

The aim of this pamphlet is to provide general information. It is not a substitute for advice from your doctor and does not contain all the known facts about PCOS. Read this pamphlet carefully, and save it for reference. Use this pamphlet only in consultation with your doctor.

Terms in this pamphlet may need further explanation by your doctor, who will be pleased to answer questions. It may be helpful to make a list of questions. If you have concerns about treatment, recovery or complications, discuss them with your doctor.

Your doctor cannot guarantee that treatment will meet all of your expectations or that treatment has no risks. You may wish to seek a second opinion from another specialist.

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- changes in the lining of the uterus (endometrium) that could increase the risk of endometrial disorders and, uncommonly, cancer of the uterus.

PCOS can be managed effectively by a variety of strategies. With early diagnosis and good management of PCOS, a patient's long-term health risks can often be prevented or delayed.

High levels of male hormones cause many symptoms of PCOS. The exact reason for the increase in male hormones is unknown, but it may relate to a genetic disorder. For example, many women with PCOS have a close blood relative (such as a sister) who also has PCOS.

It is not clear whether the condition is solely hereditary, because sisters who grow up in the same family home also share the same environment and tend to have similar dietary and exercise habits.

Poor diet and lack of regular exercise may contribute to a worsening of PCOS. Of those women with PCOS, about seven in 10 have weight-management problems.

People who are overweight tend to produce too much insulin. High levels of insulin may prompt the ovaries in some women to make large amounts of male hormones.

DIAGNOSIS OF PCOS

Diagnosis requires tests to measure the levels of hormones in the blood. Diagnosis depends on the detection of fluctuations in hormones, not simply the presence of polycystic-appearing ovaries. In some women, PCOS can be difficult to diagnose.

Diagnosis of PCOS typically requires confirmation of two of the following (in the absence of other conditions):

1. polycystic ovaries on ultrasound imaging (about one-fourth of all women have an appearance of polycystic ovaries on ultrasound imaging but do not have PCOS and are normal)
2. irregular periods
3. increased hair growth or increased blood testosterone.

Some symptoms of PCOS mimic symptoms of other hormonal disorders. No two women with PCOS have the same symptoms and signs. Not every woman with PCOS symptoms has polycystic ovaries. The reason for this is unclear.

Your doctor will need your complete medical history and may perform a physical examination. The following also may be needed:

- blood tests to check hormone levels
- blood tests to check blood sugar and lipid levels
- vaginal ultrasound to look for follicles on the ovaries and to check the thickness of the endometrium
- additional tests to help rule out other medical conditions.

TREATMENT OPTIONS TO MANAGE POLYCYSTIC OVARIAN SYNDROME

The aim of medical treatment is to manage PCOS symptoms and reduce the risk of long-term complications such as diabetes, heart disease and uterine cancer.

The treatment recommended by your doctor depends on the type and severity of your symptoms, and whether you wish to remain fertile. You may need a combination of treatments and long-term follow-up to address metabolic risks, lifestyle modifications and psychological support.

LIFESTYLE CHANGES

Whatever the symptoms, lifestyle changes are the cornerstone of medical treatment for those overweight women with PCOS. In most patients, lifestyle changes are often considered the most important treatment for PCOS and will be recommended even if you and your doctor decide to investigate other treatment options.

If a woman is overweight (body mass index greater than 30 kg/m^2), then losing five to 10 percent of her body weight may improve symptoms and help restore spontaneous ovulation. If obese, she may need to lose more to reduce the severity of symptoms.

Your doctor can give a more precise indication of the kilograms you may need to lose. Weight loss can help to:

- regulate blood sugar and insulin levels
- reduce the level of male hormones
- improve symptoms such as hirsutism, acne and alopecia
- trigger ovulation
- regulate periods
- reduce the risk of PCOS complications such as heart disease and diabetes.

Avoid crash diets because you are likely to gain weight once you return to regular eating habits. Your doctor may recommend that you follow a "diabetes diet", which includes foods with a low glycaemic index (GI) to help manage blood sugar levels. Stable levels of blood sugar tend to reduce insulin levels, which in turn may reduce the amount of male hormones made by the ovaries.

Regular exercise of 30 minutes per day helps to increase insulin sensitivity, aids in weight loss, and may lessen the severity of PCOS symptoms.

High male hormone and insulin levels can make losing weight difficult. Even if no weight is lost, do not be discouraged because healthy eating and exercise often help to manage PCOS symptoms by lowering insulin levels. Your doctor can advise you on healthy eating and exercise, or may suggest you consult other health professionals such as a dietician, physiotherapist, exercise physiologist or psychologist.

Smoking: Once PCOS has been diagnosed, the woman should stop smoking and stop the use of all tobacco products. Smoking often worsens the symptoms of PCOS. Women with PCOS who smoke report more adverse health outcomes than those who do not smoke. Quitting any use of tobacco is one of the best lifestyle changes to make.

MEDICATIONS

PCOS symptoms can be managed with medications. However, medications do not cure PCOS. Symptoms will return if you stop taking the medications.

Contraceptive pill: The contraceptive pill can regulate the menstrual cycle. Regular periods reduce the risk of endometrial cancer. Some contraceptive pills contain an "anti-androgen" medication, which can reduce male hormone levels and improve symptoms, including acne, hirsutism and alopecia. Cyproterone is an anti-androgen medicine and

TREATMENT OPTIONS *continued*

may be prescribed along with the Pill. Familiarise yourself with the risks and benefits of the Pill.

Spironolactone: The diuretic spironolactone is used to control high blood pressure and may be prescribed for its anti-androgenic effects.

Anti-diabetes drugs, (insulin-sensitising agents): These help to regulate the levels of insulin in the blood, which lowers blood glucose and male hormone levels. This may trigger ovulation. Insulin resistance can be managed in some PCOS patients by metformin (or similar drugs), which helps cells to take in and use glucose. However, metformin is not routinely prescribed. It may be prescribed in select patients.

Intrauterine hormones: In some women with persistent menstrual bleeding problems and PCOS, an intrauterine contraceptive device (IUCD) with a synthetic progesterone may help. Your doctor will discuss this option if it applies to you.

Other medications: Your doctor may prescribe other drugs to manage symptoms, antihypertensive medications for high blood pressure, or cholesterol-lowering agents in women with PCOS who have high levels of low-density "bad" cholesterol.

Side effects of medications

All drugs can have unwanted side effects. Possible side effects of medications used to treat PCOS may include, among others:

- **Contraceptive pill**
  weight gain with some pills, deep vein thrombosis (DVT)
- **Cyproterone acetate**
  depression, tiredness, reduced sex drive; not recommended during pregnancy
- **Spironolactone**
  not recommended for women who wish to become pregnant because of the risk of birth defects
- **Gonadotrophins**
  stomach pain, nausea, vomiting, diarrhoea, breast tenderness or pain
- **Clomiphene citrate**
  fatigue, eye problems, conception of twins or triplets, large ovarian cysts (ovarian hyperstimulation syndrome)
- **Anti-diabetes drugs (metformin and others)**
  diarrhoea, nausea, vomiting, low blood sugar levels.

Carefully read the Consumer Medicine Information (CMI) leaflet that comes with each medication. If your medication does not have a CMI, ask your pharmacist for one. See your doctor promptly if a medicine is causing a side effect. Your doctor may alter the dose, prescribe a different medication or suggest a different treatment.

FERTILITY TREATMENT

If pregnancy is desired, the doctor may refer you to a fertility specialist. Initial treatment includes finding out whether you are ovulating. If you are not ovulating, the specialist may suggest that you first try lifestyle changes such as regular exercise, healthy eating and weight loss.

If lifestyle changes fail to trigger ovulation, the specialist may recommend various medical tests. These tests help to determine whether PCOS is the only reason for your infertility. Fertility drugs such as clomiphene or gonadotrophins (FSH) may then be prescribed. Due to clomiphene's effectiveness and low side-effect profile, it is the treatment of first choice for women with PCOS who do not ovulate.

Metformin may be used, which decreases some of the effects of excess insulin.

Gonadotrophins are effective, but need skill in monitoring to avoid the development of too many eggs.

Assisted reproduction (such as in vitro fertilisation, IVF) is an option for couples who have other associated fertility problems or in whom ovulation induction has been difficult or unsuccessful.

Although various fertility treatments can assist in achieving pregnancy, a pregnant woman with PCOS may face increased health risks for both herself and the baby during pregnancy, especially if her body mass index is greater than 35 kg/m^2.

Therefore, certain fertility treatments may not be advisable for women with a body mass index of 35 or more, unless advised otherwise by their doctor.

Fertility drugs do have the risk of multiple pregnancy because too many eggs may be released during ovulation.

OBSTRUCTIVE SLEEP APNOEA

PCOS has been linked to obstructive sleep apnoea (OSA). OSA is a disorder where breathing stops briefly during sleep. OSA disrupts normal sleep patterns and can lower the levels of oxygen in the blood. OSA can lead to high blood pressure, mood changes, heart disease and increased weight. Signs of OSA include abnormal drowsiness and fatigue during the day, difficulty staying focussed and alert, and persistent snoring. If you have any signs or symptoms of OSA, your doctor may recommend a sleep study to diagnose whether you have OSA or another sleep disorder. Effective treatments are available.

BARIATRIC SURGERY

The link between PCOS and obesity is strong. Bariatric (weight-loss) surgery to treat PCOS may be an option for some women who have not been able to lose significant weight despite several attempts at using medically proven diets. While bariatric surgery will not cure PCOS, substantial weight loss can often restore regular menstrual periods and significantly reduce the number and severity of symptoms. However, the benefits of bariatric surgery should be compared against the surgical risks.

Substantial weight loss (of at least 10 kilograms) can often help to:

- restore ovulation
- restore periods
- improve fertility
- reduce insulin resistance
- improve health before and during pregnancy
- reduce risks during pregnancy
- reduce anxiety and depression
- reduce risks of cardiovascular disease and diabetes.

COUNSELLING

For many women, counselling has been important in managing PCOS. If you want more information about counselling, your doctor would be pleased to discuss it with you and refer you to a counselling agency or professional counsellor. PCOS support groups can be helpful. Your doctor may have information about a group in your area. Some rural areas may not have these services.

ALTERNATIVE THERAPIES

Medical studies have not shown any alternative therapy to be an effective treatment for PCOS. Tell your doctor if

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you are taking any alternative medicine as this may affect prescribed treatments.

LONG-TERM OUTCOMES

PCOS is a life-long condition that must be monitored. You will need to see your doctor regularly. It is important to manage PCOS symptoms to reduce the risk of complications.

Do not rely on PCOS as a form of contraception. Use contraception if you do not wish to get pregnant.

Most women with mild PCOS are fertile and become pregnant with or without medical assistance.

PCOS does not end at menopause. Male hormone levels drop slightly as a woman nears menopause, which may allow the menstrual cycle to become more regular. However, male hormone levels may be high enough to cause PCOS signs and symptoms.

FOLLOW-UP OF PCOS

The following should be monitored:

- the woman's gynaecological health
- weight loss and maintenance of ideal body weight
- regular exercise and daily activities
- the risk of diabetes
- signs of premature heart disease
- levels of blood fats
- medications to manage high blood pressure, cholesterol, insulin levels, hormone levels and other conditions
- emotional wellbeing and mental health.

LAPAROSCOPIC OVARIAN SURGERY TO INDUCE OVULATION

For women of child-bearing age who do not ovulate, laparoscopic ovarian surgery (LOS) is a procedure that may be suitable in some patients. No surgery can treat PCOS, but LOS can help to induce ovulation in some women with PCOS. This procedure is also called laparoscopic ovarian drilling (LOD).

LOS is occasionally used in PCOS patients with other symptoms. The aim is not to treat the cysts but to destroy a small portion of each ovary by "drilling" four to 10 holes into each ovary.

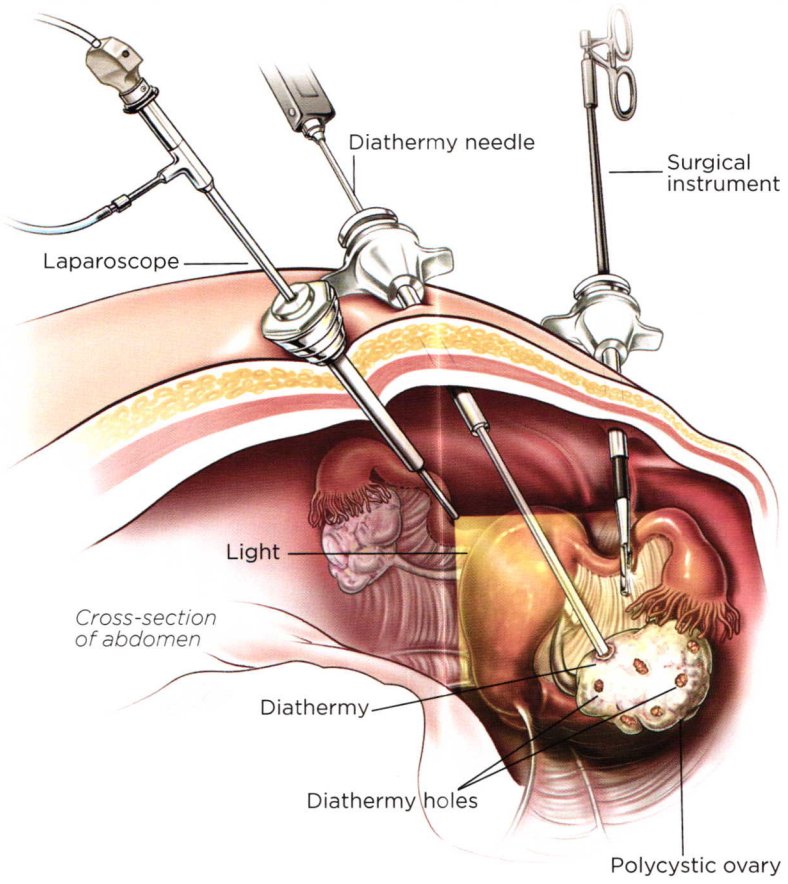
The surgeon uses a diathermy (heat) needle as shown (right), or a laser device. Both the diathermy needle and laser techniques appear to achieve the same outcomes.

While it is not clear why LOS works, doctors have found that damage to a small amount of ovarian tissue tends to reduce male hormone levels and helps to restore normal or nearly normal function of the ovaries.

The only benefit of LOS is to provoke ovulation; it is not a treatment for PCOS. Repeated procedures of LOS are not recommended, except in the most unusual cases.

While success rates have been good, LOS is not a cure. Beneficial effects may be temporary, lasting about six months.

LOS is performed using "keyhole surgery" (laparoscopy). A laparoscope is inserted through an incision in the patient's navel. Surgical instruments are inserted through additional small incisions. After treatment, the instruments are removed and incisions are stitched closed. The patient education pamphlet "Laparoscopy – a guide for women" contains more detailed information and is available from your doctor.



About half of the women undergoing LOS require additional treatment to induce ovulation, which typically is clomiphene.

MORE INFORMATION

For readers who want more information, Australian government-approved guidelines are available.

To view the guidelines, visit the website www.clinicalguidelines.gov.au or browser search "NHMRC PCOS guidelines".

Costs of treatment

It is best to discuss costs with the doctor before treatment rather than afterwards. The doctor can give you an estimate of hospital, surgical and anaesthetic fees. Ask the doctor about costs that may be covered by public healthcare or private health funds. As the course of actual treatment may differ from the proposed treatment, the final account may vary from the estimate. Extra costs may apply if further surgery is needed to treat complications.

YOUR DOCTOR

This patient education has been reviewed by obstetricians and gynaecologists in Australia and New Zealand

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