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Polycystic ovarian syndrome (PCOS)

Introduction

This leaflet has been given to you to help answer some of the questions you may have about your polycystic ovarian syndrome (PCOS) diagnosis.

PCOS is a health problem that can affect a woman's menstrual cycle, fertility, hormones, insulin production, heart, blood vessels and appearance. Women with PCOS have these characteristics:

- High levels of male hormones, also called androgens.
- An irregular or no menstrual cycle.
- May or may not have many small cysts in their ovaries. Cysts are fluid filled sacs.

PCOS is the most common hormonal reproductive problem in women of childbearing age.

How many women have PCOS?

An estimated 5 to 10% of women of childbearing age have PCOS.

About PCOS

Women with PCOS develop a number of cysts inside 1 or both ovaries. Normally, 15 to 20 follicles begin to mature for ovulation every month. Usually, one follicle fully matures and the rest die off. Women with PCOS however never have one follicle fully mature. As a result 15 to 20 follicles stay inside the ovaries and become cysts. These cysts produce high levels of male hormones causing a number of unpleasant symptoms.

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What causes PCOS?

No one exactly knows the cause of PCOS. Evidence suggests there is a genetic link to this disorder. Certain factors appear to play a role in this syndrome. They include:

- Low FSH (Follicle Stimulating Hormone) - this is a hormone released by the pituitary gland in your brain. It helps the follicles inside your ovaries to mature enabling ovulation.
- Excess male hormones – most women with PCOS have high levels of male hormone. This interferes with ovulation and contributes to PCOS.
- Insulin resistance – a large number of PCOS are insulin resistant. Insulin resistance happens when your body does not manage insulin properly. Insulin is important for proper ovarian function - this is why insulin resistance can contribute to PCOS.

What are the symptoms of PCOS?

- Infrequent menstrual periods, no menstrual periods and or irregular bleeding.
- Infertility or inability to get pregnant.
- Increased growth of hair on the face, chest, stomach, back, thumb or toes.
- Acne, oily skin or dandruff.
- Weight gain or obesity, usually extra weight around the waist.
- Male pattern baldness or thinning hair.
- Skin tags, or tiny excess flaps of skin in the armpits or neck area.

What are the complications of PCOS?

- Infertility – because PCOS interferes with ovulation you can have long term fertility problems.
- Endometrial cancer – PCOS can cause the inner lining of your womb to become thicker, increasing your risk of developing endometrial cancer.
- Obesity related illness – because PCOS increases your chance of being overweight, it causes weight related health illness such as high blood pressure, diabetes and heart disease.

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Getting the symptoms under control at an earlier age may help to reduce these risks.

What tests are used to diagnose PCOS?

Diagnosis is based on a physical examination and a number of clinical tests. Your gynaecologist will provide a pelvic examination to look for swelling of your ovaries. They will also take a blood sample to check your hormone levels and possibly arrange an ultrasound in order to get a detailed picture of your ovaries and the endometrium (inner lining of your womb).

What is the difference between PCO and PCOS?

The term polycystic ovaries (PCO) describe the appearance of the ovaries seen on ultrasound, but there are no symptoms or hormone findings. About 20 in every 100 women in the general population have ovaries with this appearance.

What is not known from the current evidence is whether these women will develop a full blown PCOS in the future.

How is PCOS treated?

Because there is no cure for PCOS, it needs to be managed to prevent problems. Treatments are based on the symptoms you are having and whether you want to conceive or need contraception.

Common PCOS treatment options include:

Weight loss - this will help to regulate insulin levels and help to restore ovulation and menstrual cycles.

Birth control pills – if the pills contain oestrogen and progesterone they will help to regulate the menstrual cycles and decrease the appearance of hair growth and acne. The menstrual cycle will become abnormal again when the pills are stopped. You may also think of taking a progesterone only pill. This will help to prevent endometrial problems but will not help to reduce acne and hair problems.

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Diabetes medication - metformin affects the way insulin is processed in the body. It also helps to decrease the testosterone level (male hormone level). This may help to restore ovulation and lessen hair growth, see leaflet GHPI0467 Metformin and subfertility.

Fertility medications - Clomid® or Letrozole or injections of Gonadotropins (hormone injections) may help to stimulate ovulation and increase your chances of getting pregnant.

Medicine for increased hair growth and extra male hormones - if you are not trying to get pregnant, medical treatments such as Cyproterone acetate, Spironolactone, Finasteride and Vaniqa® cream have been shown to reduce male hormone effects on hair growth. All treatments must be continued for 8 to 18 months before a response is expected. This is due to the slow rate of hair growth. Other non-medical treatments such as electrolysis or laser hair removal are effective at getting rid of hair.

Surgery - ovarian drilling is often an effective procedure that helps to stimulate ovulation. During surgery small holes are made in the ovary which helps to reduce the testosterone level (male hormone level) and increase ovulation. Ask for a copy of leaflet GHPI0462 Laparoscopic Ovarian Diathermy (LOD).

Does PCOS change at menopause?

Researchers are looking at how male hormone levels change as women with PCOS grow older. They think that as women reach menopause, ovarian function changes and menstrual cycle may become more normal. But, even with falling male hormone levels, excessive hair growth continues and male pattern baldness or thinning hair gets worse.

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If you have any questions, please feel free to contact the fertility nurses through Mrs K Reddy's secretary on the number below. Alternatively, please contact your consultant's secretary.

Cotswold Fertility Unit

Tel: 0300 422 3128

Monday to Friday, 8:00am to 4:00pm

Website: www.cotswoldfertilityunit.co.uk

Gloucestershire Domestic Abuse Support Service (GDASS)

This is a county-wide service offering a variety of support programmes for women and men over 16 years old who are experiencing domestic abuse.

Tel: 01452 726 570

Monday to Friday, 9:00am to 5:00pm

Domestic Violence Helpline

Tel: 0808 2000 247 (24 hours)

Email: support@gdass.org.uk

Website: www.gdass.org.uk

Further information

Further information can be found at the following website:

Women's Health

Website: www.womens-health.co.uk

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Making a choice

Shared Decision Making

If you are asked to make a choice, you may have lots of questions that you want to ask. You may also want to talk over your options with your family or friends. It can help to write a list of the questions you want answered and take it to your appointment.



Ask 3 Questions

To begin with, try to make sure you get the answers to three key questions if you are asked to make a choice about your healthcare.

1. What are my options?
2. What are the pros and cons of each option for me?
3. How do I get support to help me make a decision that is right for me?

These resources have been adapted with kind permission from the MAGIC Programme, supported by the Health Foundation* Ask 3 Questions is based on Shepherd HL, et al. Three questions that patients can ask to improve the quality of information physicians give about treatment options: A cross-over trial. Patient Education and Counselling, 2011;84: 379-85

<https://aqua.nhs.uk/resources/shared-decision-making-case-studies/>