PCOS Mythbusting (Polycystic Ovary Syndrome)





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What is PCOS?

Polycystic ovary syndrome (PCOS) is a common condition, said to affect 8-10% of the female population.

PCOS affects how your ovaries work. Normally an egg is released once a month and this is called ovulation. PCOS can have an impact on this and cause irregular ovulation, or no ovulation at all, meaning irregular, infrequent or absent periods are common symptoms of PCOS.

PCOS can also affect your metabolism (the chemical reactions in the body's cells that change food into energy) making it easier to gain weight and more difficult to lose weight.

For information on PCOS visit NHS Inform: https://www.nhsinform.scot/healthy-living/womens-health/girls-and-young-women-puberty-to-around-25/periods-and-menstrual-health/polycystic-ovary-syndrome-pcos

Watch the ALLIANCE and Scottish Government webinar on PCOS: https://www.youtube.com/watch? v=ncEWCvyiGV4&list=PLDgTzLd2QrJG9IRcU715S5_XgPiUeH4gw&index=6

You can also watch this short animation by the MRC Centre for Reproductive Health at the University of Edinburgh on NHS Inform or via this YouTube link:

https://www.youtube.com/watch?v=PtPRMjR7XIE

Common PCOS myths

BUSTED! People with PCOS have cysts on their ovaries

People with polycystic ovaries do not have cysts on their ovaries. PCOS affects ovulation and so, instead of the ovaries releasing an egg each month, the eggs pause and the follicles that hold the egg build up in the ovary. On a scan, these paused follicles with the eggs look like dots on the ovary. These were mistakenly called cysts and this is how the condition got its slightly misleading name.

But PCOS is not just about having polycystic ovaries (paused eggs). Actually, not everyone with PCOS will have polycystic ovaries, and having polycystic ovaries alone does not mean you have PCOS.

This is because to be diagnosed with PCOS you must have at least two of these three things:

- Polycystic Ovaries (a build up of paused follicles containing eggs) these can be seen via an ultrasound scan
- Slightly higher levels of 'male' hormones in your body (androgen) this can cause symptoms like excess facial or body hair or acne
- An irregular menstrual cycle It can be helpful to keep a note of your period dates and symptoms using a calendar, a diary or an app.

BUSTED! If you have irregular periods you have PCOS

Irregular periods can be caused by lots of different things, for example hormonal changes like menopause or taking hormonal contraception, but they can also be caused by underlying health conditions as well as PCOS.

Your body's hormones control the menstrual cycle. When the level of the estrogen hormone in the body increases the lining of the womb thickens and the ovaries will release an egg (ovulation).

In the second half of the cycle, the levels of progesterone hormone will increase. This stops the lining of the womb from continuing to grow and gets the womb ready for pregnancy. If pregnancy doesn't occur, estrogen and progesterone levels will drop. This hormonal change causes the lining to be shed from the womb which causes a period.

With PCOS, this hormonal cycle is out of balance and the ovary does not release an egg regularly, progesterone levels don't increase and the lining of the womb continues to grow. This is why some people with PCOS have heavy and prolonged bleeding when they do have a period.

Those with PCOS need three or four periods a year to keep the womb lining healthy and protected - unless you are taking hormonal contraception with progesterone. In this case then it is OK to not have a period as progesterone will keep the lining healthy.

Hormonal contraception like the combined pill (the pill), progesterone only pill (mini pill), hormone coil or implant is not just for preventing unwanted pregnancy, it can also be a really useful tool to manage irregular periods, and other symptoms associated with PCOS.

They can help to manage your menstrual cycle and protect the lining of the womb. You can have regular periods or if you prefer you can take the pill continuously and have no period at all. The combined pill will lower the male type hormone and can also really help if your PCOS means you experience acne for example.

You can find out more about irregular periods on NHS Inform: https://www.nhsinform.scot/healthy-living/womens-health/girls-and-young-women-puberty-to-around-25/periods-and-menstrual-health/irregular-periods

BUSTED! Everyone with PCOS will gain weight

Lots of people with PCOS are not overweight.

But PCOS can affect your metabolism (the chemical reactions in the body's cells that change food into energy) making it easier to gain weight and more difficult to lose weight. Exercise has been proven to improve PCOS symptoms, even without weight loss, and there are strategies available to help you maintain a healthy diet.

There are no specific diets that should be used in PCOS, but low GI diets, with more vegetables, fruits and pulses (such as chick peas and beans) and less sugary things seem to work better in the longer term. It is thought that it is better to have small meals regularly and to have more calories at the start of the day when you are active afterwards, rather than later in the day when you are less active afterwards.

BUSTED! PCOS makes you infertile

People with PCOS still release eggs (ovulate), just irregularly, and in fact, for people with PCOS ovulation can become more regular with age. So, if you don't want to become pregnant you should still use contraception.

If you have PCOS and would like to start planning a pregnancy there are straightforward ways to improve your fertility chances. There is also increased fertility immediately after stopping the contraceptive pill. PCOS does not mean you are any more likely to need complex fertility treatment such as IVF. These treatments can be very effective but there is weight limit to accessing treatment.

For more information on fertility and planning pregnancy see the charity Tommy's: https://www.tommys.org/pregnancy-information/planning-a-pregnancy/fertility-and-causes-of-infertility

BUSTED! PCOS symptoms cannot be improved

PCOS is a lifelong condition and there is no cure, but there are lots of ways to manage PCOS symptoms at different stages of life including:

- **Hormonal contraception** to manage your menstrual health, keep the lining of the womb healthy and help with other symptoms like acne.
- Maintaining a healthy weight through healthy diet and exercise to improve symptoms and support overall health.
- Considering your long term health including heart health.
- Supporting your mental health and wellbeing.

See NHS Inform for more information on supporting your overall health: https://www.nhsinform.scot/healthy-living/womens-health/middle-years-around-25-to-50-years/womens-heart-health/womens-heart-health
Resources are available on NHS inform which can help your mental health: https://www.nhsinform.scot/self-help-quides/self-help-tool-periods-and-mental-

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FAQs

If I use hormonal contraception to manage PCOS do I still need to have a period 3 – 4 times a year to keep my womb healthy?

Hormonal contraception like the combined pill (the pill), progesterone only pill (mini pill), hormone coil or implant is really good at managing PCOS symptoms. These types of contraceptives contain the hormone Progesterone which keeps the womb lining healthy even if you do not have a period while you take them.

Is contraception the only way to get progesterone, or is there another way to take the hormone?

It is important to have three or four periods a year to keep the womb healthy. Progesterone can be prescribed separately, so if you are not using hormonal contraception (the pill, mini pill, hormone coil or implant) then you should speak to your doctor about the best options for you.

Are weight loss pills and injections good to support weight loss for PCOS? Weight loss injections work by reducing appetite. For most people with PCOS appetite is not the driver of weight gain, instead it is metabolic and hormonal imbalance, and exercise has been proven to improve PCOS symptoms, even without weight loss. There are some studies showing that weight loss injections can work in PCOS but it is likely they work better when appetite is the main driver of weight gain.

Is Metformin a good solution for treating PCOS?

Metformin can be used to try to make the metabolic imbalance a bit better in PCOS. It can increase energy levels and make the periods a little more frequent. Metformin itself doesn't cause weight loss but it has been suggested that if you are losing weight through lifestyle changes then Metformin can facilitate a longer duration of weight loss. Some people with PCOS really benefit from Metformin, others see no change and some stop because of prolonged gastrointestinal side effects. It is difficult to predict who will respond best to Metformin. It is not as good for fertility as standard fertility treatments though and not as good for the skin or periods as hormone treatment.

Are there any links between PCOS and heart health?

There is evidence that people with PCOS can have an increased risk of cardiovascular disease in later life. This can be due to increased weight, increased fats in the blood, and increased blood pressure. Those with PCOS, especially those over 50, can ask for their blood pressure to be checked at their GP.

You can find more information about women's heart health on NHS Inform: https://www.nhsinform.scot/healthy-living/womens-health/middle-years-around-25-to-50-years/womens-heart-health/womens-heart-health Information on high blood pressure can be found here: https://www.bhf.org.uk/informationsupport/risk-factors/high-blood-pressure

Can supplements, for example myo-inositol, improve PCOS?

Studies into the role of food supplements for PCOS are largely anecdotal and are not subject to the same rules and regulations as studies which look at the effectiveness of medicines. If you are taking supplements and feel you a benefit from doing so then it's unlikely to be doing any harm.

Is PCOS hereditary?

PCOS does run in families, but research exploring the causes of PCOS is still ongoing.

Are there links between PCOS and ovarian cancer?

There are no known links between PCOS and ovarian cancer.

Is there a link between PCOS and thyroid conditions?

There may be a weak link between PCOS and thyroid conditions, in particular underactive thyroid.

For information on both an underactive and overactive thyroid see NHS Inform. https://www.nhsinform.scot/illnesses-and-conditions/glands/underactive-thyroid/ https://www.nhsinform.scot/illnesses-and-conditions/glands/overactive-thyroid/



Is it normal to have back problems with PCOS?

Pain in the pelvis and back are uncommon in PCOS.

Why am I so tired with PCOS?

There are lots of reasons for tiredness that don't relate to PCOS or hormones. However there are two things that are more likely in PCOS that are associated with tiredness. The increased hormone of storage (insulin) can promote energy storage rather than usage and that can reduce energy particularly after eating. Those with PCOS sometimes have poor sleep because of a condition called sleep apnoea which is more common in those with PCOS, particularly if they are overweight. It can be associated with snoring, gasping and waking up multiple times during sleep.

Information on sleep apnoea can be found on NHS Inform: https://www.nhsinform.scot/illnesses-and-conditions/lungs-and-airways/obstructive-sleep-apnoea/

How can I get support for PCOS?

NHS Inform provides expert online information on PCOS symptoms, diagnosis and treatment as well as signposting to charities than can offer further support. People with PCOS do not necessarily need to see a specialist, and support can be provided by visiting your GP.

When visiting my GP for PCOS what information should I draw to their attention?

Tell your GP about your menstrual history including the shortest and longest time between periods, and the heaviness of your bleed. It is also helpful to share information about other symptoms such as acne or extra hair growth.

How can health professionals better understand, diagnose and treat PCOS? If you are a healthcare professional and you would like to understand more about PCOS, diagnosis and treatment you can access this clinical paper: https://pubmed.ncbi.nlm.nih.gov/24591680/

