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Is adenomyosis the cause of your heavy, painful periods?

BBC newsreader Naga Munchetty has recently shared her adenomyosis diagnosis after 35 years of not knowing the cause for her severely painful, heavy periods and vomiting.

Menstrual cramps are something many of us handle with painkillers, warm baths and a hot water bottle. For some women, though, extremely painful, heavy periods are caused by a lesser-known condition which can have a serious impact on their lives.

Adenomyosis is where the tissue that grows on the lining of the uterus - the endometrium - is also present on the inside muscular wall of the uterus. Nobody knows exactly how many are affected, but the NHS estimates it is one in 10 women in the UK.

What is adenomyosis?

Narendra Pisal, consultant gynaecologist at London Gynaecology, says adenomyosis occurs when the tissue that normally lines the uterus grows into the muscular wall of the uterus. During menstruation, the displaced tissue acts normally and thickens, breaks down, and bleeds. This causes an enlarged uterus and painful, heavy periods.

"Sometimes the uterus is so enlarged that a lump can be felt in the lower tummy (abdomen)," Pisal says. "It can also cause pressure on the bladder and bowel, causing you to pee more (urinary frequency) and constipation. However, some women may not have any symptoms."

"Unbearable pain" due to adenomyosis

Rebecca*, 53, had adenomyosis when she was in her 40s.

"It started with pain that was unbearable in my abdomen and extended down into my right groin," she says. "Pain seemed to even get into my legs at times. It was worse around periods but, honestly, it seemed to hurt all the time."

Rebecca was told she had irritable bowel syndrome (IBS), a hernia, and also long lasting (chronic) unidentified nerve pain in her leg, before being referred to a gynaecologist.

"I was told it was probably perimenopause for two years, before finally saying I now deserved an MRI scan as I had been patient, but not to expect anything," Rebecca says.

The scan revealed she had adenomyosis. At 47, Rebecca decided to have a full hysterectomy, during which the surgeon also found she had endometriosis - a condition where tissue similar to the womb lining grows in other places, such as the ovaries and fallopian tubes.

Adenomyosis vs endometriosis

Although women with adenomyosis can also have endometriosis, they are different conditions. With endometriosis, endometrial tissue - the tissue that lines the inside of the womb - is found outside the uterus - for example, on the Fallopian tubes or the ovaries.

We don't know exactly why adenomyosis happens, but there are several theories.

"There may be an increased risk if there has been some injury to the womb. The most common injury is caesarean section," says Dr Virginia Beckett, a gynaecologist and spokesperson at the Royal College of Obstetricians and Gynaecologists.

When the lining of the womb tries to heal itself after the C-section, it is suggested that the re-growth happens inwards instead of outwards, leading to adenomyosis.

"But it can certainly happen in women who haven't had any injury to the womb," Beckett adds.

Other factors may include your genes, hormones and immune system. It's important to remember it is nobody's fault if adenomyosis occurs - and there is no known way to prevent it.

How is adenomyosis diagnosed?

Unfortunately, many women that have adenomyosis go for a long time without a diagnosis. This is in part because women with adenomyosis may have different symptoms, or because the symptoms – such as pelvic pain – can be caused by other conditions too, such as pelvic inflammatory disease. Others may not seek medical advice, believing the pain is normal.

"Many women live with this condition without ever having a diagnosis made," Pisal says. "A lot of women with adenomyosis have such bad periods that they have to put their life on hold for that time of the month. It affects quality of life significantly. It can lead to anaemia due to heavy bleeding and lead to extreme tiredness."

Adenomyosis can be detected by an ultrasound scan, or in some cases, by a magnetic resonance imaging (MRI) scan, which uses magnets and radio waves to produce an image of the inside of your body.

"It's a difficult condition in that until a few years ago, it was only a diagnosis that you made in a pathology lab – once you had had the uterus under a microscope, you could see the symptoms were caused by it," Beckett explains. "Around 50% of cases can be diagnosed now with ultrasound because it's much more finely tuned and sensitive to picking up things like this. However, some people might need an MRI scan to determine adenomyosis."

How is adenomyosis treated?

There are lots of options when it comes to treating adenomyosis, although many address the symptoms, such as pain, rather than the underlying cause. Other factors may influence your decision too, such as your age and whether you want children, as adenomyosis also improves during and after pregnancy and after menopause.

Pisal says: "Supportive treatment is often the first line of management with medication to make the periods less painful (such as mefenamic acid) and to reduce the bleeding (tranexamic acid)."

"Sometimes taking the mini pill, or using the contraceptive pill back to back can also stop the periods and help with the symptoms. Mirena intrauterine system (IUS) is also helpful in reducing the symptoms significantly."

You can also have injections of hormones to make a temporary and reversible 'false' menopause but they can't be used long-term.

Beckett says: "A GnRh analogue, which essentially switches the ovaries off and makes you temporarily menopausal, can shrink down the tissue that is causing the problem."

Another treatment for adenomyosis, called uterine artery embolisation, involves having small particles injected into your blood vessels through a catheter in the groin, which can cut off the blood supply to the adenomyosis. It has been found to be effective in the short to medium term, and there are no major safety concerns. Although this is less invasive than surgery and may preserve fertility, symptoms may come back in the future.

Hysterectomy, surgery to remove the womb, may be an option for women who do not want to become pregnant.

Although a healthy diet, stretching, yoga, and gentle exercise may help with period pain, more research is needed to find out how effective they are against adenomyosis.

Why haven't people heard of adenomyosis?

One issue is that a large proportion of women have heavy and painful periods and accept the symptoms as normal.

"There's a lot of 'oh my Mum had heavy periods, that's just the way it is' and 'women's curse' and that kind of thing, but it's not necessary to feel like that anymore," Beckett says. "There is a huge amount that can be done depending on the stage you are at in your life. Speak up - that would be my biggest advice."

Often, women don't know how painful their periods are supposed to be.

"When they do seek medical attention, often the doctors would start medical treatment to control symptoms and a scan may not be carried out or may not actually pick up the condition," Pisal says.

"There are many other causes of heavy and painful periods such as fibroids and endometriosis which are more widely known," he adds. "In fact, both fibroids and endometriosis often co-exist with adenomyosis."

Another risk is that symptoms of adenomyosis are dismissed as merely period pain.

"More doctors and women are now aware of this condition, and increasing availability of ultrasound scans will lead to a higher detection rate," Pisal adds. "This is good news as early diagnosis will help in prompt treatment and improving the quality of life for these women."

Further reading

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