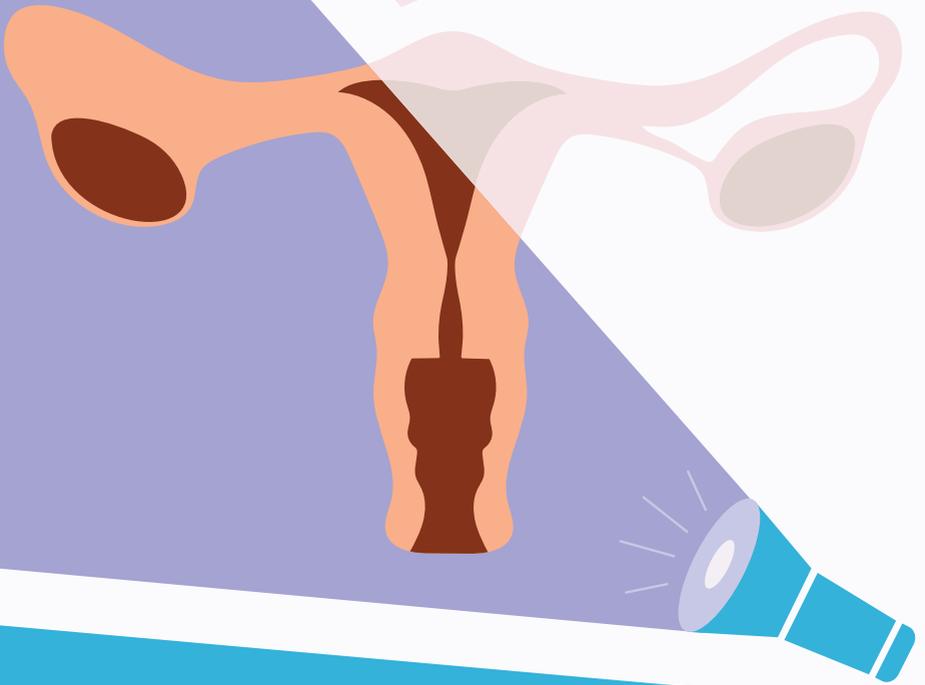


Adenomyosis and You



**A GUIDE TO
THE PERIMENOPAUSE AND MENOPAUSE
IF YOU HAVE ADENOMYOSIS**

This booklet is designed to give practical advice and support about the perimenopause and menopause for those with a diagnosis of adenomyosis. It has been written and reviewed by Newson Health group healthcare professionals.

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What is adenomyosis?

Adenomyosis occurs when the tissue that is the same as the tissue lining your womb (endometrial tissue) appears in the muscular wall of your womb (uterus).

This tissue continues to act in the same way as the lining of your womb does and thickens, breaks down and then bleeds, during your period. This can lead to heavy, painful periods and an enlarged uterus. You may experience pain at other times to your periods too.

Adenomyosis is a relatively poorly understood condition by doctors and researchers, but more information is being discovered all the time.

How common is adenomyosis?

It is difficult to know exactly how many women are affected by the condition, as there has been little research about it in the past and the condition may not cause symptoms at all in some women. However, the figures around the number of women affected are increasing as diagnosis improves through better scanning techniques.

A UK study of almost 1,000 women having scans for gynaecological problems including infertility and irregular bleeding found that almost 21% had adenomyosis¹. Meanwhile a large US study suggested almost 1% of women (0.8%) could be affected, rising to 1.5% for women aged between 41 and 45 years (2).

Causes

Adenomyosis, like endometriosis, is caused by tissue from that is the same as the tissue lining your womb being found in the wrong place.

Why this happens isn't yet fully understood. One theory is that cells from the lining of your womb could invade the muscles that form it, possibly triggered by surgery to your womb such as a Caesarean section, while some researchers suggest that this tissue is deposited in your muscle of your womb when your womb is first formed when you were a foetus.

Another theory is that there might to be a link between adenomyosis and childbirth. Swelling in your womb lining after giving birth might disrupt the normal barrier between cells that line your womb and those in the muscle walls.

But, however adenomyosis develops, symptoms usually depend on levels of the hormone estrogen, which controls your periods.

Risk factors

Again, this is an emerging area of research, but it seems that there are certain factors that put you at higher risk of adenomyosis.

These include multiple pregnancies or prior surgery to the womb.

Some research suggests women who breastfeed appear to have slightly lower rates of adenomyosis, possibly due to a halt in their periods and therefore having less estrogen in the body.

Symptoms of adenomyosis

According to NICE guidance on heavy menstrual bleeding, health professionals should consider adenomyosis if you have significantly painful periods, and have a large, tender uterus on examination.

Adenomyosis can cause heavy periods which last a long time and a feeling of pressure in your stomach and bloating.

Other symptoms include pelvic pain, pain during sex, and infertility. However, you could also have the condition and have few or no symptoms at all.

How does adenomyosis differ from endometriosis?

Both these conditions involve tissue that is the same as the tissue lining your womb (endometrial tissue) being in the wrong place.

With adenomyosis, this tissue grows within the muscular walls of the womb. In endometriosis, it grows outside the uterus and may involve the ovaries, fallopian tubes, pelvic area and bowel. Adenomyosis is more likely to cause heavy period bleeding than endometriosis, and endometriosis is often associated with other symptoms(4).

Research suggests that if you have one of these conditions, you are more likely to have the other: One study in Germany which looked at MRI scans of women found that 80% of those with adenomyosis had endometriosis, and 91% of those with endometriosis had adenomyosis(5).

Diagnosis

If you have symptoms of adenomyosis, your first step should be to make an appointment to see your GP (6).

They should ask you about the nature of your period bleeding, your other symptoms, such as pelvic pain and the impact on your quality of life. Your GP will likely want to examine you to see if you have a bulky, tender uterus, and may advise a blood test to check your haemoglobin (blood count) and iron levels to check that you have not become anaemic or have a low iron level from heavy bleeding. If your doctor thinks you are likely to have adenomyosis they are likely to refer you for a transvaginal ultrasound scan

This is where a small ultrasound probe is carefully passed into your vagina, so that the womb can be more closely studied. Internal examinations may cause some discomfort, but don't usually cause any pain and tend to last about 5-10 minutes.

A magnetic resonance imaging (MRI) scan may be needed in some cases. MRI scanning was previously considered the best way to establish a diagnosis of adenomyosis but ultrasound now is steadily becoming the preferred imaging, thanks to its increasing accuracy and ease of access.

Treatment

If you are struggling with the symptoms of adenomyosis, there are a number of treatments which can help, including medication, devices and surgical options which you should talk through with your healthcare professional.

Endometrial cells, whether growing in the wrong or right place, respond to hormones, so medicines to regulate your hormones can help with symptom control.

In simple terms, the hormone estrogen stimulates the cells to grow, while the hormone progesterone (or a synthetic version known as progestogen) prevents the womb lining from thickening and keeps the cells thin and healthy.

Mirena coil

The first option for most women is an intrauterine system (IUS), known as the Mirena coil. This is a small, T-shaped plastic device with a coating of a progestogen placed in your womb by a doctor or nurse.

The Mirena coil releases a type of progestogen and is mainly used as a contraceptive, but it also reduces heavy, painful periods. Once in place it lasts for up to five years.

You should give the Mirena coil at least six months to see if it helps with your symptoms.

Prescription and over the counter medication options

If the Mirena coil doesn't ease symptoms, medication options often include tranexamic acid, a prescription medication which controls bleeding, and anti-inflammatory medication to relieve pain, such as ibuprofen.

Oral contraceptive pill

Then there are oral hormonal options, such as the combined oral contraceptive pill (which contains both estrogen and progestogen) or the progestogen only pill, known as the mini pill. Oral progestogens can stop your periods altogether, which can be beneficial if you have painful periods.

Surgical options

If none of these options work for you, or your symptoms are very severe, a surgical approach could be considered.

Endometrial ablation is a procedure to thin or remove the lining of your uterus and is one possible treatment for adenomyosis. This is carried out to reduce heavy periods and is normally carried out as a day-case with a local anaesthetic. It will reduce bleeding but is unlikely to help with pain and can on occasion make it worse.

Another option is a hysterectomy, which is the removal of the womb.

You should only consider these surgical options after discussing the risks and benefits with your doctor. A hysterectomy ends your fertility, and pregnancy is unlikely and not recommended after endometrial ablation, due to a higher risk of complications(9).

The perimenopause and menopause explained

The menopause is when the ovaries stop producing eggs and levels of the hormones estrogen, progesterone and testosterone fall.

The definition of menopause is when a woman hasn't had a period for 12 months. The perimenopause is the time leading up to this and varies from months to years, when you still have periods, but the fluctuating and low hormone levels - especially estrogen - can trigger a range of different symptoms.

The average age of the menopause in the UK is 51. However, it's really important to state that it doesn't just happen in mid-life: menopause before 45 is known as an early menopause, while menopause before the age of 40 is known as premature ovarian insufficiency (POI).

Like adenomyosis, your perimenopause and menopause will be unique to you. You may sail through it and hardly notice anything, or you may feel like a completely different person and experience a range of symptoms.

Symptoms can include:

- Change in your periods, including the frequency, **pattern or flow** (during the perimenopause)
- Hot flushes
- Night sweats
- Mood changes
- Fatigue and poor sleep
- Brain fog or poor concentration
- Loss of interest in sex or relationships
- Joint pains and muscle aches
- Hair changes and skin dryness
- Worsening migraines and headaches
- Vaginal dryness and soreness
- Urinary symptoms such as needing to pass urine more often, leakages of urine or urinary tract infections



How does menopause affect adenomyosis?

The good news is symptoms of adenomyosis should improve and go when you reach menopause as your periods become less frequent and eventually stop.

As your periods will stop, this will result in ending to any painful, heavy bleeding you may have experienced before.

However, during the perimenopause there are often significant fluctuations in your hormone levels. This is when you can begin to get menopausal symptoms such as hot flushes, sweats, mood changes, anxiety, disturbed sleep, muscle pains and changes to your periods.

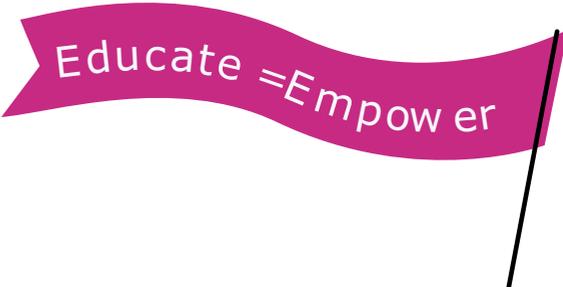
These hormonal changes can make your periods unpredictable – they may become more or less frequent, and you may bleed for longer. This means that if your periods are heavy and painful from adenomyosis, you may experience this more if your cycle is getting shorter and your periods are longer.

The perimenopause can last for up to 10 years before your periods stop altogether and it most commonly occurs when a woman is in her forties.

Living well through the perimenopause and menopause

There's lots you can do to help manage the impact of the perimenopause and menopause, including eating healthily, avoiding too much alcohol and caffeine, staying active, managing stress levels, sleeping well and doing things you enjoy regularly. Taking HRT to replace the missing hormones can be beneficial for many women too.

There is more information on lifestyle changes in the booklet titled Living well through your perimenopause and menopause on



Educate = Empower

HRT explained

HRT stands for hormone replacement therapy and is an umbrella term for the different hormonal treatments that people can take for the menopause. It usually contains the hormone estrogen, and you will need to take a progesterone/progestogen to protect the lining of your womb if you still have one.

A third hormone, testosterone, that you naturally produce, can also be used as part of HRT.

Can I take HRT if I have adenomyosis?

HRT is the first-line treatment for the management of menopause symptoms. Not only does HRT provide relief of menopausal symptoms but it also provides long term health benefits with a reduction in the risk of cardiovascular disease, osteoporosis, dementia, diabetes and bowel cancer.

If you are considering HRT, you should have a conversation with your healthcare professional about the benefits and risks of any menopause treatment based on your medical history and your personal preference. Transdermal estrogen (estrogen patches, gel or spray) does not carry any increased risk of blood clot and micronised progesterone (Utrogestan in the UK) is a natural progesterone not thought to carry any increased risk of breast cancer. This combination is what is known as body identical HRT.

Normally women who are perimenopausal will be offered cyclical HRT, where you take estrogen every day, and progesterone (or a progestogen) alongside it for the last 14 days of your menstrual cycle.

Continuous HRT, when estrogen and progesterone (or a progestogen) are given continuously throughout your cycle, rather than cyclical HRT is preferable as it is more likely to stop your periods and avoid the pain they bring. However, during the perimenopause this may not be possible as the continuous regime can lead to very chaotic bleeding. Therefore, the best option if you are perimenopausal (still having periods) and have adenomyosis, is often through the Mirena coil. This provides contraception, prevents periods and pain and once placed is effective for five years.

When it comes to HRT after the menopause, when your periods have stopped altogether, all the same options of continuous HRT should be available to you as anyone else.

Some women may find when they first start HRT, the estrogen can bring back some of their adenomyosis symptoms, as it can cause the womb lining cells within the muscle wall to bleed again. This can often be improved by adjusting your HRT dose and often does settle with time.

It is important to mention any bleeding or pain you are experiencing to your healthcare professional when you go for your review appointment about your HRT, or make an earlier appointment if you are getting bleeding which is heavy or persistent, or period type abdominal pains.

Your healthcare professional should be able to help you adjust your HRT to get the maximum benefit.

Many women find their symptoms improve within a few months of starting HRT, improving their overall quality of life.

Symptoms including hot flushes and night sweats should subside within a few weeks of starting HRT, but other symptoms, such as vaginal dryness, may take longer to resolve. Overall most women find a significant improvement in their quality of life from taking HRT and in addition benefit from the long term health benefits. Current guidance is clear that there is no maximum age for body identical HRT and this can be continued as long as a woman wishes those benefits to continue for.

Non-hormonal treatments

Herbal medicines

There are many treatments that some people find beneficial for their symptoms. However, specific remedies will not be described here as there is no good quality evidence to support their use.

Talking therapies

There is evidence to support the use of cognitive behavioural therapy (CBT) to help a variety of symptoms, mainly vasomotor symptoms and poor sleep, and improve your quality of life.

Prescribed medications

Prescribed medications are often offered for women if they do not want to, or cannot, take HRT, particularly to treat hot flushes. Examples of these are gabapentin or pregabalin and antidepressants, such as venlafaxine. Studies show that there can be reduction in hot flushes with these medications but they can have unwanted side effects such as dizziness, weight gain, sleepiness and negative effects on sexual arousal.

References

- 1 Upson, K, and Missmer, S.A, (2020), 'Epidemiology of adenomyosis', *Seminars in Reproductive Medicine*, 38 (2-03), pp.89-107. doi:10.1055/s-0040-1718920
- 2 Yu, O. et al. (2020), 'Adenomyosis incidence, prevalence and treatment: United States population-based study 2006-2015', *American Journal of Obstetrics and Gynecology*, 223 (1), e1-94. doi:10.1016/j.ajog.2020.01.016
- 3 NHS Inform (2022), 'Adenomyosis', <https://www.nhsinform.scot/healthy-living/womens-health/girls-and-young-women-puberty-to-around-25/periods-and-menstrual-health/adenomyosis>
- 4 NHS.uk (2022), 'Endometriosis', www.nhs.uk/conditions/endometriosis
- 5 Leyendecker, G., Bilgicyildirim A., Inacker M., et al. (2015), 'Adenomyosis and endometriosis. Re-visiting their association and further insights into the mechanisms of auto-traumatisation. An MRI study', *Archives of Gynecology and Obstetrics*, 291(4), pp.917-32. doi:10.1007/s00404-014-3437-8
- 6 National Institute for Health and Care Excellence (2018), 'Heavy menstrual bleeding', www.nice.org.uk/guidance/ng88/chapter/Recommendations
- 7 National Institute for Health and Care Excellence (2018), 'Heavy menstrual bleeding', www.nice.org.uk/guidance/ng88/chapter/Recommendations
- 8 Royal College of Obstetricians and Gynecologists 'Endometrial ablation recovering well patient information leaflet', www.rcog.org.uk/for-the-public/browse-all-patient-information-leaflets/endometrial-ablation/
- 9 Ibiebele, I. et al. (2021), 'A study of pregnancy after endometrial ablation using linked population data', *Acta Obstetrica et Gynecologica Scandinavica*, 100 (2), pp. 286-93. doi:10.1111/aogs.14002

This booklet has been reviewed by healthcare professionals from Newson Health Group.
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