

PAIN MANAGEMENT FOR ENDOMETRIOSIS

This booklet explains what you can do to help manage your endometriosis pain.

It includes helpful information on pain treatments, managing pain at work as well as how to make sex more comfortable and much more.

ENDOMETRIOSIS^{UK}

HEAT AND COMFORT

Heat helps to relax the muscles so you may find a hot water bottle or hot bath might help to make you feel more comfortable. Some people also find heated wheat bags or electric, wireless heat pads soothing.

PAIN MEDICATIONS

There are three common types of pain medications:

- Paracetamol
- Non-steroidal anti-inflammatory drugs (NSAIDs)
- Codeine-based medications

Speak to your pharmacist or GP for advice on which type(s) of pain medications might be most suitable for you. It is important that you explain any other health conditions that you have and any medications you are taking. Pain medication can affect how well other medicines work and might increase the risk of side effects so make sure you get the right advice for you.

Always follow the manufacturer's instructions when taking any medications.

Paracetamol

Paracetamol is a commonly used medicine that can be bought over the counter to relieve mild pain. It is often recommended as it's safe for most people to take and side effects are rare.

Paracetamol can also be used alongside other pain medications such as ibuprofen and codeine (known as co-codamol when it's combined with paracetamol).

Taking too much paracetamol, known as an overdose, can be very dangerous. Make sure you are careful not to use other medications that contain paracetamol as an ingredient (such as some cold and flu remedies) if you're taking paracetamol for pain.

Non-steroidal anti-inflammatory drugs (NSAIDs)

NSAIDs are available as tablets, capsules, suppositories (capsules inserted into the bottom), creams, gels and injections. Some, like ibuprofen or Voltarol (diclofenac) can be bought over the counter from pharmacies. Others like Ponstan (mefenamic acid) need a prescription.

Although NSAIDs are commonly used, they're not suitable for everyone and can sometimes cause some side effects. Tablets or capsules should normally be swallowed with water or food to stop them upsetting your stomach. NSAIDs can also cause nausea, vomiting, diarrhoea, and stomach ulcers. If you experience any troublesome side effects, stop taking the medication and tell your doctor.

For more information please see: www.nhsinform.scot/tests-and-treatments/medicines-and-medical-aids/types-of-medicine/nsaids

NSAIDs and Endometriosis

NSAIDs work by blocking the production of prostaglandins in your body. Prostaglandins occur naturally in your body and have several functions, one of which is making the uterus (womb) contract during your period. This helps with the shedding of the womb lining (the blood from your period) but can also cause painful cramps.

It is thought that women with endometriosis may produce more prostaglandins than women without the condition.

You can take this type of medication when your pain starts but NSAIDs work best when they are taken before your body produces prostaglandins (before your pain starts).

It can be useful to use a period tracker app or a calendar so that you can work out when to expect your period and which day your pain is likely to start. If you know which day your pain is likely to start you may want to consider taking NSAIDs the night before.



Opioid Medication

Opioid medication such as co-codamol (paracetamol and codeine) or tramadol can sometimes be prescribed by a doctor for severe pain. They can be very effective but can become less effective over time and often have side effects, including:

- Constipation
- An upset stomach
- Long-term dependence

These side effects often get worse if you take these medications for a long period of time or take them a lot.

It is important to discuss any concerns you might have with your doctor so you can decide what is best for you.

PAIN MODIFYING MEDICATIONS

Tricyclic antidepressants (for example, amitriptyline) are medications that can be used to treat depression. These medications have also been found to have an effect on the way the body responds to pain. They are only available on prescription, so your GP can discuss whether they are suitable for you and answer any questions you might have.

TRANSCUTANEOUS ELECTRICAL NERVE STIMULATOR (TENS) MACHINES

TENS machines can be small, discreet machines with sticky pads (electrodes) that you attach to your skin. The machine sends mild electrical pulses into your body which can feel mildly ticklish but should not hurt. The electrical impulses may help relieve pain, relax muscles and stimulate the production of endorphins, which are the body's natural painkillers.

A TENS machine only provides relief while it is being used but you may feel it's worth trying instead of, or in addition to, other treatments.

While TENS machines are generally very safe, they are not suitable for everyone. Always check with your GP before trying a TENS machine, especially if you have a heart condition, have epilepsy or may be pregnant.

PAIN MANAGEMENT PROGRAMMES

Some Health Boards have pain management programmes with a special clinic providing advice and support to people with chronic pain.

At a pain clinic, there will be a team of experts that can help you with the physical symptoms of endometriosis, including bowel urgency, incontinence and painful sex, as well as the impact that endometriosis has on your mental health.

Your GP can signpost you to services that are available in your area.

THERE ARE LOTS OF THINGS YOU CAN TRY TO MANAGE YOUR PAIN. SPEAK TO YOUR GP ABOUT THE OPTIONS AVAILABLE TO YOU.



HORMONE TREATMENTS

Hormone treatments don't treat pain, but they do help to manage the endometriosis itself. They work by stopping the ovaries (a part of the female reproductive system) from producing oestrogen (female sex hormone) which is thought to stimulate the endometriosis. Many people find their symptoms are worse around the time of their period and so stopping your periods with hormone treatment can help.

Hormone treatments include the combined oral contraceptive pill, progestogen only pill (the mini pill), intrauterine system (IUS, commonly called the coil), a patch or injection. These are contraceptives meaning that they prevent pregnancy so consider if this is right for you. Sometimes you might need to try different types of hormonal contraceptives to find the right one for you.

GnRH analogues are sometimes used if other hormonal treatments haven't helped to manage your symptoms. They reduce the production of oestrogen and put your body in temporary menopausal-like state. They are not a contraceptive and so you need to use a condom or diaphragm when you have sex to avoid pregnancy.

For detailed information on hormone treatments, you can visit:
www.endometriosis-uk.org/hormone-treatments-endometriosis



SURGERY

Surgery can remove the deposits of endometriosis. Some people find surgery improves their pain symptoms but for others it does not. It is also possible that the endometriosis may grow back and so some people may need further surgery.

After surgery, gentle exercises, yoga or Pilates can be helpful to support your recovery.

You can discuss whether surgery is suitable for you with your gynaecologist. If you would like a referral to a gynaecologist, talk to your GP.

**FOR MORE INFORMATION
ON THE DIFFERENT TYPES
OF SURGERY, OR TO VIEW
OUR VIDEO ON SURGERY FOR
ENDOMETRIOSIS VISIT:
[WWW.ENDOMETRIOSIS-UK.ORG/
SURGERY-ENDOMETRIOSIS](http://WWW.ENDOMETRIOSIS-UK.ORG/SURGERY-ENDOMETRIOSIS)**

PELVIC FLOOR EXERCISES

Your pelvic floor muscles sit at the base of your pelvis. They help to keep your bladder, uterus, vagina and bowel (pelvic organs) in the right place. Your pelvic floor muscles should be kept strong and active, just like any other muscle.

You can learn how to exercise your pelvic floor here:

www.nhsinform.scot/healthy-living/womens-health/middle-years-around-25-to-50-years/pelvic-health/pelvic-floor-muscles/

PAINFUL SEX

Experiencing pain during sex or afterwards is a common symptom of endometriosis and its medical name is dyspareunia.

The pain that is felt is different for everyone and can range from a deep ache to a short sharp stabbing pain.

Why does it hurt?

Endometriosis can cause scar tissues inside the pelvis which becomes thickened and can stick together. When you have sex, the movement can pull or stretch the scar tissue, causing pain. It can be particularly painful if your endometriosis is behind your vagina or around your rectum (the end section of your large intestine).

If you have felt pain during sex before, you might feel tense because you are preparing for it to hurt. This may make you tense your pelvic floor muscles which can make sex feel more uncomfortable.

Remember that you're not causing harm

If something causes pain, it's easy to think that it's causing harm or damage but having sex is unlikely to be making anything worse. With this in mind, you may feel more comfortable trying new ways to make sex more enjoyable.

WHAT CAN YOU DO ABOUT IT?

Consider different positions

Sometimes it can hurt in one sexual position more than others and some might not hurt at all. Try different positions to see which is most comfortable for you. Some people find that being on top so they can control the depth of penetration or raising their hips on a cushion in the missionary position, is more comfortable. Having gentler, slower sex may also help.

Use a lubricant

Anxiety around sex, as well as some of the hormonal medications that are used to manage endometriosis can cause vaginal dryness making sex uncomfortable or painful. Using a lubricant can help with this and are easily available at the pharmacy or supermarket.

There are different types of lubricant including water-based (a good choice if you have sensitive skin or are prone to UTIs), silicone-based or oil-based (which should not be used with condoms as it can damage them).



Reframe what it means to have sex

Sex does not have to involve penetration. There are many ways to stimulate sexual pleasure for each of you, including oral sex, using your hands or using sex toys. Kissing, cuddling and physical closeness also add to feelings of physical intimacy.

See a pelvic-health physiotherapist

Pain during or after sex may not just be because of the endometriosis itself but muscular weakness, spasm or nerve sensitivity in the pelvic-floor muscles that has developed over time.

A pelvic-health physiotherapist can work with you to explore the causes of your pain and give you tools to help with managing it. This includes things like:

- using mindful breathing exercises to help relax the pelvic floor
- giving you stretches for the pelvic area
- advising on external and internal massage to reduce fear and sensitivity

Your GP can advise on whether this service is available in your area of Scotland. There is a detailed webinar on sex and the exercises that can help at www.endometriosis-uk.org

Consider counselling

It can be hard to address the issue of sexual pain without also exploring the emotional impacts of it, such as fear and anxiety, guilt or low self-esteem. Counselling can really help, and can be for you alone or as a couple.

You can find out more about counselling and therapies at www.nhsinform.scot/tests-and-treatments/counselling-and-therapies/



DIET AND NUTRITION

You may have read that certain diets can help to manage endometriosis. There is very little high-quality evidence for this. However, some people find foods that cause bloating or constipation, like beans, broccoli, milk and other dairy products and fizzy drinks can make their pain worse, particularly if they experience bowel symptoms from their endometriosis. It is important to note that what works for one person may not work for another.

Endometriosis is an inflammatory condition, so it's thought that the anti-inflammatory effects of the Mediterranean diet may help reduce pain and symptom severity. The Mediterranean diet is high in fruit, vegetables, beans, legumes such as chickpeas, wholegrains, nuts, seeds and olive oil with some fish and poultry. It limits red meat, sugar and alcohol as well as processed foods like ready meals crisps, cakes, biscuits, bacon and breakfast cereals.

Some evidence suggests that eating lots of gluten (foods like bread, cakes, biscuits), red meat, alcohol and caffeine might affect the production of oestrogen (female sex hormone) which is thought to stimulate the endometriosis so cutting back on these foods could potentially help with symptoms.

The gut microbiome (the community of trillions of bacteria that live in your gut), is a promising area of research for endometriosis because having a healthy gut microbiome is linked to reduced inflammation. Eating a diverse, nutritious, whole food diet supports a healthy gut microbiome but, you could also try fermented foods such as sauerkraut, kimchi and kefir to introduce more friendly bacteria (probiotics) to your gut. These can all be found in supermarkets and health food shops.

**TO FIND OUT MORE ABOUT THE
LATEST RESEARCH, YOU CAN
WATCH THE WEBINAR ON
ENDOMETRIOSIS AND NUTRITION
AT WWW.ENDOMETRIOSIS-UK.ORG/
RESEARCH**

PHYSICAL ACTIVITY

Research has shown that physical activity can help to reduce pain severity, particularly for painful periods (known as dysmenorrhea) as well as improving physical wellbeing. Researchers are also looking into whether physical activity might have an anti-inflammatory effect which could slow the growth of endometriosis.

We do know that physical activity releases feel-good hormones called endorphins, and this may help with pain perception. It can boost your energy levels but also help you to sleep better, which may make your endometriosis feel more manageable.

Physical activity can also help to relieve bloating and constipation, which can help you feel better if you have bowel symptoms.

Certain types of physical activity, such as yoga and Pilates, can help with either strengthening pelvic floor muscles or helping to relax tension/spasm in these muscles, which can help to relieve pain.

When you are in pain and tired, it can be difficult to exercise regularly. Swimming, yoga, Pilates, walking and cycling are good low-impact options and you can build up slowly and gently to see how your body responds.



ENDOMETRIOSIS AND WORK

It can be difficult to manage pain at work. You may find it helpful to keep an endometriosis 'first-aid' kit at work, containing, for example: painkillers, period products, spare underwear, a small hot water bottle or heat pad if you have access to a kettle or microwave, or a TENS machine.

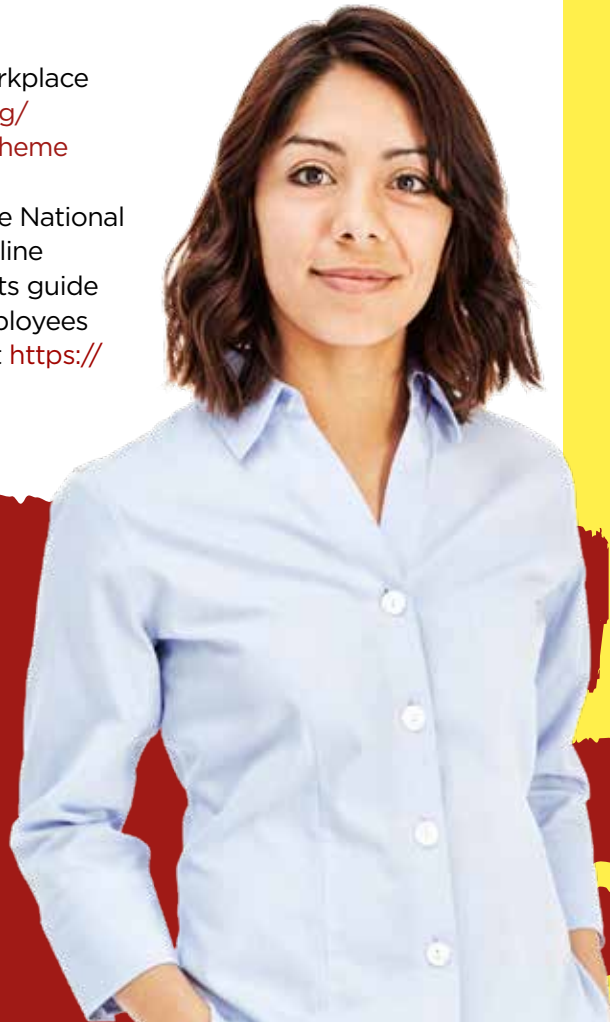
Communicating with your employer and explaining your needs is also important, this enables them to support you better and understand why you might need some time out or flexible working if you have a flare-up.

Endometriosis UK provides guidance for employers on how to support employees with endometriosis through our Endometriosis Friendly Employer Scheme.

You can find out more about our workplace scheme at www.endometriosis-uk.org/endometriosis-friendly-employer-scheme

There is also a help and advice on the National Wellbeing Hub including a guide for line managers and workplace adjustments guide as well as a workplace policy for employees of NHS Scotland. You can find this at <https://wellbeinghub.scot/resource/mmhp/>

THERE ARE RESOURCES AVAILABLE TO HELP YOU TALK TO YOUR EMPLOYER ABOUT YOUR CONDITION AND ENABLE THEM TO SUPPORT YOU BETTER.



FURTHER INFORMATION

You can visit NHS Inform for further information on pain management. NHS Inform features videos on breathing and relaxation exercises and guides on living with chronic pain and reducing stress.

You can find it here: www.nhsinform.scot/chronicpain

Scan the QR code or visit www.nhsinform.scot/healthy-living/womens-health to view the NHS Inform Women's Health Platform. It also has reliable information about a wide range of women's health topics from menstrual health to menopause, mental health and much more.



HOW WE CAN HELP

Living with endometriosis can be a daunting experience. If you're finding things difficult, we're here to help. Our trained volunteers, all with personal experience of endometriosis, can offer you the help you need to understand your condition and take control. We offer:

- Quality information and advice on endometriosis, including a series of webinars
- Emotional and practical support through our network of support groups, helpline, webchat and online forum

📄 Visit www.endometriosis-uk.org/get-support

☎ Helpline: **0808 808 2227**

Tell us what you think

You can give us feedback on all our publications by contacting us on information@endometriosis-uk.org

This booklet was designed following consultation with those affected by endometriosis in Scotland. Many thanks to those who shared their lived experiences of endometriosis and gave their time to ensure this booklet answered your questions.

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