

Patient information

# Self-Management Strategies for Chronic Pelvic Pain

This leaflet talks about self-management strategies for managing chronic pelvic pain. It has been designed to help you if you have been diagnosed with:

*Endometriosis (when the lining of the womb is found in other parts of the pelvis and body causing pain and abnormal bleeding)*

*Bladder pain syndrome (feeling of pain/pressure in the bladder area and problems with passing urine)*

*Adenomyosis (when the lining of the womb is found in the muscle layer of the womb causing pain and abnormal bleeding)*

Chronic pelvic pain where no cause has been found yet

It covers a number of things you can do yourself to help manage your pain independently. The sections cover additional techniques/ remedies and the evidence behind them.

Medical terms are highlighted in italics and are explained in a section at the end of the leaflet. There is a reference section at the end of the leaflet for further detailed reading.

### **Advice from an expert patient from her journey with endometriosis:**


“ Endometriosis can affect every woman differently, so there is no single treatment plan that is guaranteed to work for everyone. Having a balanced diet, eliminating inflammatory foods, reducing stress, exercising regularly, implementing treatment strategies and taking prescription medications (if required), can make this condition more manageable and may ease the chronic pain significantly. There may be no quick fix, genuine wellness takes time and effort. We encourage you to implement these strategies into your everyday life and make it a habit. It is about doing the right thing every day, the accumulation of which creates positive change. Follow the recommended steps in this leaflet consistently and continue to research other methods along the way to help in your journey of managing pain. ”

## What role does self-management play in management of chronic pelvic pain?

Self-management describes ways of looking after your pain without the need for health care professional advice, medications or surgery. This can empower you to be engaged in your care between appointments and medical interventions. The ideas in this leaflet will help you develop positive, problem-focussed coping strategies for managing your pain.

## What can be achieved using self-management?

Evidence (Leonardi et al) shows that women using coping strategies report lower stress levels, fewer symptoms of low mood, and less pain.



We want to help  
you to take control  
of your pain  
management

Even though these strategies have been shown to be effective, not everything will be effective for everyone, but they will help you individualise your care. There will still be medical and surgical options available when needed, and the tips in this leaflet should be used alongside them.

## What can you do yourself?

We have grouped the strategies into four categories.  
It may be helpful to keep a diary to see what works for you.

A free app that may help is (<https://flaredown.com/>)

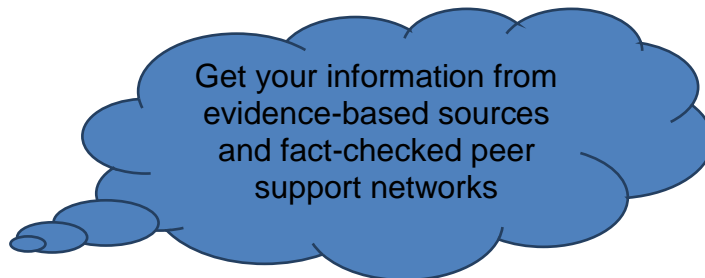
- 1) Education, time-management and social wellbeing
- 2) Exercise/physical coping strategies
- 3) Emotional wellbeing
- 4) Diet

## How can education, time-management and social wellbeing help with pain?

### Education:

You may want to understand more about the condition which is causing your pain. Some people find this helpful in managing their symptoms.

There is a lot of information on line, but not all is evidence-based (based on research results that have been reviewed for their quality). Good sources are Endometriosis UK ([endometriosis-uk.org/](http://endometriosis-uk.org/)), and the pelvic pain support network ([pelvicpain.org.uk](http://pelvicpain.org.uk)). There are also links on other causes of pelvic pain such as bladder pain syndrome in the reference section.



It may also be helpful to understand a body response called “pain memory” which is thought to be one of the reasons why chronic pain develops.

When the body experiences pain, we think that the nervous system creates a “memory” of the feeling. This means that, in the future, the nerves are very sensitive to any similar sensation, which can increase the feeling of pain for that person.

Often the feeling/pain is much stronger/long lasting than in someone who doesn’t have the pain “memory”. It also means that you may feel pain from a sensation that someone without the memory would not.

The information above is evidence-based. Please be aware that although forums on social media can be helpful, they may not always have correct and up to date information.

### **Time-Management and work:**

Openness with employers/schools and universities, as well as discussing how work/learning can be adjusted during a flare can help to reduce your anxiety about having to take time off.

You may be working/studying from home and feel that it allows you to better manage your symptoms. Now is the perfect time to lay future plans, discussing with managers how your work/studying can continue to be carried out remotely in the future if needed.

In schools and universities you can ask for extra time during exams and for extra consideration when having exams marked.

You can ask your medical team for a letter to your line manager/school/university to support reasonable arrangements. All employers are required by law to support reasonable adjustments that allow you to continue your work (Equality Act 2010).

### **Social Well-being:**

Try as much as you can to carry on with social activities within the rules of social distancing/isolation when these are in place. Examples might be meeting a friend for a walk/exercise or to connect with your community for worship.

It is possible to “attend” many experiences online/virtually now e.g., arts and culture organisations. For women dealing with chronic pain this could be useful in reducing social isolation now and in the future.

It may be helpful to schedule social activities at times when you are less likely to be experiencing a pain flare up.


There is also social support available from Endometriosis UK ([endometriosis-uk.org/](http://endometriosis-uk.org/)).

## **How can exercise and other physical strategies help?**

### **Exercise:**

Exercise is a very individual thing and you will need to find out what type and intensity of exercise works for you. Explore different types of exercise to find the

ones you like! We suggest making sure that you always use a step-wise approach to whatever exercise you choose, and set goals which are achievable and sustainable.



Allow yourself  
time to build up to  
your goals

Using the step counter on your phone is a great way to gradually increase your movement. Small goals such as building daily step totals by 100 steps are a good place to start. Some people find it helpful to walk/exercise to music/podcasts/audio-books or with a buddy.

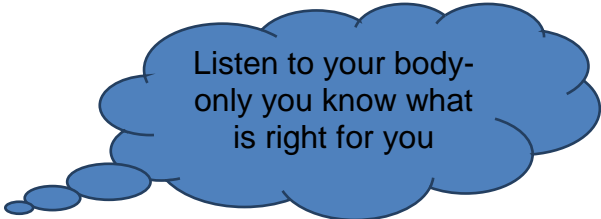
### ***Types of focussed exercise***

**Yoga** can be helpful in reducing pain in women with *endometriosis*, as well as helping with pain where there is not a clear diagnosis. We recommend using instructors/poses especially geared towards managing *endometriosis*/pelvic pain as certain poses are not recommended.

The following links to Yin yoga and restorative yoga are especially recommended-

[\(http://yogayin.com/endometriosis-yoga/\)](http://yogayin.com/endometriosis-yoga/)

<https://tinyurl.com/24vxz5k9>

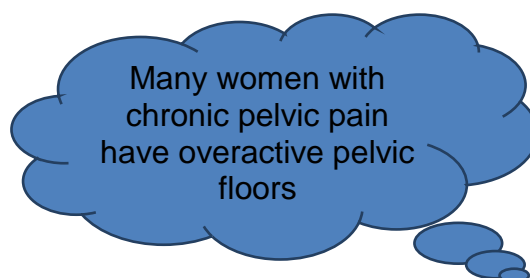


Listen to your body-  
only you know what  
is right for you

Remember to listen to your body and try to recognise when you may be doing too much. It's better to try little and often rather than doing too much and not wanting to try again.

**Pelvic floor exercises/relaxation** and breathing exercises can support your healing process. Try the “simple pelvic exercise programme” from Endometriosis UK.

Some exercises can worsen pain, so the following section is a suggested gentle practice from one of our specialist physiotherapists.

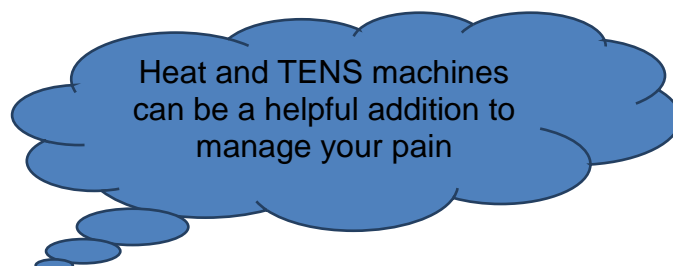


“To help relax your pelvic floor you can try lying down on your back with your knees bent and feet supported, or lying on your side. Make sure that your stomach feels soft and that you are not pushing your stomach out. Make sure that you are not holding your breath!

Now place your hands on your stomach and try and breathe into your belly, getting your hands to rise and fall. Do this a couple of times. Now follow this by doing a couple of mini pelvic floor squeeze and releases. You can try and do this regularly throughout the day.”

**Heat:**

Consider applying heat packs to help manage pain symptoms. Some people suggest adhesive patches but deep heat creams can also be really useful!



**TENS Units:**

A TENS unit sends electrical pulses through the skin and helps your body to release endorphins which are the body’s own natural painkillers.

In women with pelvic pain these electrical signals help to block the painful signals being sent to your brain.

A TENS unit can be bought in any pharmacy.

To use a TENS unit, stick 2 of the pads at the same level on your lower tummy or low/mid back (whichever works best for you).

A pad on the lower central tummy may help with bladder pain. Make sure pads are stuck down well and not peeling off.

Choose a setting (constant or burst). High frequency settings work better for pelvic pain. Set the current so that you can feel it but so that it is not uncomfortable.

Once your body gets used to the sensation you can increase the current and should keep doing so until it is at the highest tolerable level (ideally 80-100Hz). Try to leave it on for around 20-30 minutes.

## How can you help boost your Emotional Wellbeing?

### **Sleep:**

Sleeping helps us to cope better with the physical and psychological symptoms that are common in women who suffer from chronic pain.

Try to get 7-9 hours of sleep per night. It may help to remove things that cause noise, light and distractions in bed (e.g., smartphones). Avoiding caffeine after lunch will help you get better quality sleep.

Try to “switch-off” electronic devices 2-3 hours before you sleep.

For more information on sleep and ways to improve this, search for The Sleep Foundation ([www.sleepfoundation.org/](http://www.sleepfoundation.org/))

### **Mindfulness and Relaxation:**

Some people relax by listening to music/ relaxation tracks/ religious content.

Mindfulness, progressive muscle relaxation and breathing exercises can all help with chronic pain symptoms.

You can do these things at home using an app on your smartphone. Please see the reference section for relevant apps.





## What dietary changes may help with my chronic pelvic pain?

The FODMAP (Fermentable Oligosaccharides, Disaccharides, Monosaccharides and Polyols) diet may help to reduce certain symptoms such as bloating that are troublesome to many women with chronic pelvic pain.

Following this diet involves cutting out different food groups one at a time. For example:

Dairy: Milk (cow/goat/sheep), yoghurt, soft cheese

Pulses: Beans, lentils, dhal, hummus/chickpeas

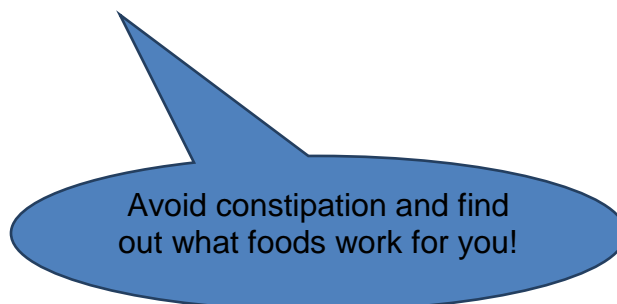
Gluten/Wheat: Bread, pasta, cous-cous, biscuits, but not in “free from” food

These are just examples of the groups and there is a more detailed list of foods in the references at the end of this leaflet.

By removing one group at a time, it is easy to identify if there is an improvement. If there is no change with stopping one group of foods, they are unlikely to be increasing your symptoms and so you can consider eating them again.

If you suffer with pelvic pain it is important to try to avoid constipation by having a good amount of fluids and fibre (such as ispaghula/psyllium husk and linseed).

Linseed can be added to almost any dish, including breads, biscuits, cakes, cooked or uncooked snack bars, muesli mixes, porridges, and even to curries and vegetable stews.



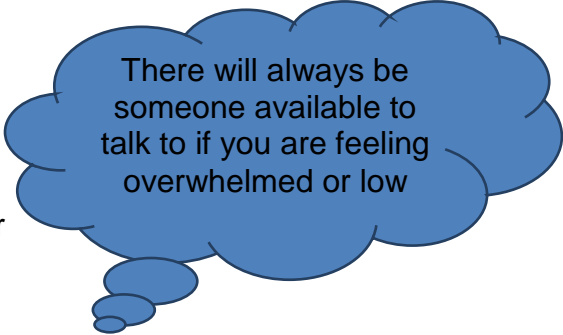
It can also help to keep a diet/bowel-movement/symptom diary to identify the foods causing symptoms. If you have a rounded diet it is not necessary to take supplements, unless you are specifically *deficient* in anything e.g. Iron/Vitamin D.

## What do we hope this leaflet will achieve?

We hope that these ideas can be used with medications and surgical options to help you to cope with your symptoms, and the impact they have on your physical and psychological health.

We hope that they may improve control of your symptoms even if there is more limited access to healthcare services (for example, during the Covid-19 pandemic).

If you feel at any point that you are not coping, then you should contact your named healthcare provider (for physical symptoms). This could be either your GP for more general concerns or your hospital team if there is a problem related to specialist treatments or surgery.



There will always be someone available to talk to if you are feeling overwhelmed or low

If you are experiencing low mood or thoughts of self-harm, or if you just need someone to talk to then “The Samaritans” offer a free 24 hour impartial and non-judgemental support service. You may contact the Central London Samaritans on 116 123 (free from any phone).

## Definitions

Endometriosis - a condition where the lining of the womb is found in a number of places outside the cavity of the womb where it is supposed to be

Adenomyosis - a condition where the lining of the womb is found in the muscle layer of the womb where it is not supposed to be

Bladder pain syndrome - pain/ discomfort in the pelvis/bladder with associated urinary symptoms, lasting more than 6 weeks and with no identifiable cause

Pelvic floor - the set of muscles that sit at the bottom of the pelvis. They hold up your internal organs and help you to control the bladder/bowel

Deficiency - when you do not have enough of something e.g. iron, causing anaemia

## References:

Leonardi et al. Self-Management Strategies to consider to combat endometriosis symptoms during the Covid-19 Pandemic. Human Reproduction Open, pp. 1-11, 2020. doi:10.1093/hropen/hoaa028

[www.endometriosis-uk.org](http://www.endometriosis-uk.org) The Endometriosis UK website has links to informative webinars, information and guides, and how to access local support groups in your area

[www.pelvicpain.org.uk](http://www.pelvicpain.org.uk) The pelvic pain support network

<http://www.cobfoundation.org/bladder-conditions/interstitial-cystitis-painful-bladder-syndrome>

[www.nhs.uk/conditions/interstitial-cystitis](http://www.nhs.uk/conditions/interstitial-cystitis)

<https://science.howstuffworks.com/life/inside-the-mind/emotions/remember-pain.htm>

[www.sleepfoundation.org/](http://www.sleepfoundation.org/)

The following are links to free yoga videos:

<http://yogayin.com/endometriosis-yoga/>

<https://tinyurl.com/24vxz5k9>

The following is a link to a technical discussion about the use of TENS

[https://m.youtube.com/watch?v=SGXCEkZZu\\_Q](https://m.youtube.com/watch?v=SGXCEkZZu_Q)

The following are links to sites that can help with use of the FODMAP diet:

<https://www.bbcgoodfood.com/recipes/collection/low-fodmap-recipes>

<https://www.bbcgoodfood.com/howto/guide/what-low-fodmap-diet>

<https://alittlebityummy.com/34-low-fodmap-dinner-recipes/>

The following apps offer a free trial period but after that move to a subscription service:

“Headspace” <https://www.headspace.com/>

Mindful website <https://www.mindful.org/meditation/mindfulness-getting-started/>

“Curable” <https://www.curablehealth.com/>

“Flaredown” <https://flaredown.com>

The following is the link and number for the Samaritans:

<https://www.samaritans.org/> - Samaritans Helpline (Phone 116 123 for free)

The following is the link to contact PALS (patient advice and liaison service) at Bart’s Health:

[www.bartshealth.nhs.uk/pals](http://www.bartshealth.nhs.uk/pals)

**Books:**

Heal Pelvic Pain by Amy Stein

A Headache in the Pelvis by Amy Stein

Endometriosis: The Experts’ Guide to Treat, Manage and Live Well with your Symptoms by Professor Horne and Carol Pearson

Gut: The Inside story of our body’s most under-rated organ by Giulia Enders

This leaflet is a product of co-development between the Specialist Endometriosis team of Royal London Hospital and expert patients with years of experience managing this condition.

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## Large print and other languages

This information can be made available in alternative formats, such as easy read or large print, and may be available in alternative languages, upon request. For more information, speak to your clinical team.

এই তথ্যগুলো সহজে পড়া যায় অথবা বৃহৎ প্রিন্টের মতবকিল্প ফরম্যাটে পাওয়া যাবে, এবং অনুরোধে অন্য ভাষায়ও পাওয়া যতে পারে। আরো তথ্যের জন্য আপনার ক্লিনিকিয়াল টিমের সাথে কথা বলুন।

Na żądanie te informacje mogą zostać udostępnione w innych formatach, takich jak zapis większą czcionką lub łatwą do czytania, a także w innych językach. Aby uzyskać więcej informacji, porozmawiaj ze swoim zespołem specjalistów.

Macluumaadkaan waxaa loo heli karaa qaab kale, sida ugu akhrinta ugu fudud, ama far waa weyn, waxana laga yabaa in lagu heli luuqaado Kale, haddii la codsado. Wixii macluumaad dheeraad ah, kala hadal kooxda xarunta caafimaadka.

Bu bilgi, kolay okunurluk veya büyük baskılar gibi alternatif biçimlerde sunulabilir, ve talep üzerine Alternatif Dillerde sunulabilir. Daha fazla bilgi için klinik ekibinizle irtibata geçin.

آسان مین پڑھنے کے لیے چیسائی، سکتی جاکی دست یاب میں فارمیٹس متبادل معلومات یہ پرنٹ بڑا یا اور درخواست پر متبادل زبانوں میں بھی دستیاب ہو سکتی ہیں۔ مزید معلومات کے لیے، اپنی کلینکل ٹیم سے بات کریں۔

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Leave feedback on NHS Choices [www.nhs.uk](https://www.nhs.uk)

## Patient Advice and Liaison Service (PALS)

Please contact us if you need general information or advice about Trust services:

[www.bartshealth.nhs.uk/pals](https://www.bartshealth.nhs.uk/pals)

**Reference:** BH/PIN/1088

Publication date: All our patient information leaflets are reviewed every three years.