



York and Scarborough
Teaching Hospitals
NHS Foundation Trust

Pelvic Pain Toolkit

Information for patients, relatives and carers

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Introduction

You are receiving this toolkit because you are living with persistent pelvic pain. It suggests strategies to help you manage this condition. It aims to provide some tools that can help improve your symptoms. Pain pathways are complex, but there are many things everyone can do to improve their symptoms. The toolkit includes the following topics:

- Acceptance
- Goal Setting
- Pacing
- Relaxation
- Breathing
- Mental Health
- Keep Physically active
- Socialising, relationship and support systems
- Diet
- Enjoyment and distraction
- Complimentary therapies
- Sex and intimacy
- Other resources

Firstly, here is a great, easy-to-use video about chronic pain: Understanding Pain in less than five minutes, and what to do about it

https://www.youtube.com/watch?v=C_3phB93rvI.

Why is the pelvic pain toolkit important?

Persistent pain is often something that people live with for many months or even years. It impacts all aspects of life including work, family, and intimate relationships. It can be challenging to treat even with specialist treatments. Therefore, it is important to find additional tools that work for you and support your wellbeing and minimise the impact on your quality of life.

What can you do to help yourself?

This diagram illustrates a holistic approach to managing pelvic pain, highlighting key self-care strategies that can improve well-being and reduce the impact of pain on daily life. Each entry represents an important aspect of pain management, ranging from physical activities like exercise and breathing techniques to emotional support and lifestyle adjustments. In the following sections, you will find an explanation of each of these elements in detail, providing practical guidance on how to incorporate them into your daily routine for effective pelvic pain management.

Acceptance

Acceptance is an important aspect to living with persistent pain and long-term conditions. Many people who are suffering with persistent pain find it very hard to accept that there is no cure. It can be hard to recognise that life cannot go on exactly as it would have done without the pain.

However, People can learn strategies that enable them to continue to live well, alongside their pain. These are some of the strategies which, used together, can help to give better long-term relief. Every small thing that you can change may add up to a significant improvement in your experience of living with pain.

Goal setting

Setting targets for each day and for the longer term can keep the body and mind active. This can help clarify your progress and aims through your recovery. As with any recovery, it is important to choose goals that matter to you - for example, being able to do the shopping or driving the car. In time, these goals can become more challenging, but you can break them down into small and manageable steps. Recording your goal and progress can also help.

Pacing

Strides: Goal Tracker is a free, flexible app that allows you to track all your goals and habits with reminders and charts to keep you motivated. Visit their website at www.stridesapp.com.

Carrying on physical activity to the point of unmanageable pain or exhaustion is rarely helpful. It is tempting to try and finish things or 'push through the pain' but this usually makes pain or tiredness worse and is discouraging. Pacing means spreading out activities through each day.

Taking regular breaks, changing position, briefly resting between activities, or doing stretches throughout the day can help.

Regularly setting goals and using pacing techniques can help you achieve many of the activities that persistent pain may have 'stolen' from you. Also try to think about what is realistically achievable and small wins.

Relaxation

Practising relaxation techniques regularly can reduce persistent pain. It is a useful skill to have but takes time to develop. Learning to relax can help you sleep and cope well with stressful and difficult situations. There are many books, CDs, or videos on relaxation techniques. Visit their website at <http://www.paincd.org.uk> is a non-profit self-help CD for people who suffer persistent pain.

Good sleep and sleep hygiene is very important. Avoid computer screens an hour before bedtime, maintain regular waking and bedtime hours, have a regular bedtime routine such as enjoying a bath or reading, avoid caffeine after 4pm and consider a caffeine-free alternative hot drink before bedtime. This video on improving our sleep explains more:
<https://www.youtube.com/watch?v=mgewmltNEPs>.

There are many apps which are free to download, make sure you 'try before you buy' before purchasing any upgrade. Find one that makes your daily routine easier not harder.

Headspace is a popular mindfulness and meditation app. Mindfulness is the ability to be fully present in the moment and leads to decreased stress and after sadness, to increased levels of focus and happiness. Visit their website at www.headspace.com.

Calm is an app for sleep, relaxation, and mindfulness meditation, built to help you feel calm in a natural way that is in tune with your body's ability to switch from 'ready for action' to 'resting.' To get the app visit: www.calm.com.

Portal - Focus, Sleep, Escape is a mindfulness app with a difference. Instead of guided meditations, it transports users around the world, helping them chill out with assistance to from before some of nature's most relaxing sounds. To get the app visit: www.portal.app

Smiling Mind is a free mindfulness meditation app geared to bring balance to your life. Every session starts by asking you to assess your mood based on three criteria: happiness, contentedness, and alertness. At the end you are left 'with a smile on your mind'! To get the app visit: www.smilingmind.com.au

Breathing

Stress and pain can lead us to breathe incorrectly, taking short, shallow breaths from our chest. This type of breathing causes unpleasant symptoms such as tension, dizziness, a racing heart, difficulties concentrating, chest tightness and pins and needles.

The correct way to breathe is from the abdomen not the chest. When you breathe in your tummy should move out a little, when you breathe out, your tummy should fall in slightly. Your upper chest should stay still at all times. Relaxed, slow breathing from the tummy helps you stay calm and relaxed. Many people with pain report that learning to breathe correctly is particularly helpful.

Progressive muscle relaxation and breathing exercises can be undertaken at home using a variety of websites and/or audio downloads. One example can be found at: www.beyondblue.org.au/mental-health/wellbeing/relaxation-exercises.

Mental Health

Living with daily pain is physically and emotionally stressful. Chronic pain is known to change the levels of stress hormones and neurochemicals found within your brain and nervous system; these can affect your mood, thinking and behaviour. Disrupting your body's balance of these chemicals can lead to depression and anxiety, which in turn exacerbates pain symptoms. Please speak with your General Practitioner if you are troubled by these problems.

Mind is a mental health organisation which promotes wellbeing and recovery, provides a wide range of advocacy services, delivers training courses, offers a confidential helpline most evenings including the weekend and encourages recovery through volunteering.

Local Minds run mental health services in local communities. This link will take you to your Local Mind. www.mind.org.uk/information-support/local-minds/

SAM (Self-help App for the Mind) is a free app to help you understand and manage anxiety. To get the app visit www.mindgarden-tech.co.uk.

Happify app aims to improve your emotional wellbeing, whether you feel stressed, anxious, or depressed. You can pick from a range of free 'tracks' depending on what you want to improve. This includes overcoming negative thoughts, feelings on career success, and building self-confidence. To get the app visit www.happify.com

Keep physically active

Research indicates that staying active can help people with persistent or chronic pain feel better and help them to do more. Physical activity also increases the level of endorphins (natural pain killers) in our body, reducing pain the natural way. They also boost mood and improve mental health. Movements or activities that can make pain worse do not necessarily involve further damage or injury. It is very important to understand this, as it means that being active may hurt but this does not mean you are getting injured or harmed. Understanding this can help you recover and get back some of the life you may have lost to persistent pain.

To do this with being active usually involves improving general fitness. Low impact exercises initially such as stretching or walking. Yoga has been associated with a reduction in levels of chronic pelvic pain and improvement in quality of life. Alternatives may be swimming or cycling.

Socialising, relationships and support systems

Having contact with people can play an enormous part in helping you feel better. Pain can make it hard to get out to see people or to join in with what they are doing, but social contact can be at home, over a cup of tea, within whatever limits you have. It has been shown that keeping in touch with friends and family is good for our overall health.

Young Minds offers information and advice to young people, parents and carers. Whether you want to understand how you are feeling, find ways to feel better, or support someone who is struggling, they are here to help. www.youngminds.org.uk

Relate provides relationship counselling. It has a searchable database of local registered counsellors. Visit their website at www.relate.org.uk

Diet

What you eat and drink can play a role in pain relief. It is especially important for those suffering with persistent pain to have a healthy, balanced diet. For most people, there is no evidence that excluding food groups from your diet helps with pain. However, if you find that removing something from your diet improves your symptoms then it is worth avoiding this food type provided you are still eating a balanced diet. Guidance on a balanced diet can be found below.

There is emerging evidence that changing your gut microbiome may improve mental health and alleviate some pain conditions. The gut microbiome is the mix of different organisms (bacteria and fungi) in your bowel.

The balance of “good” and “bad” organisms in your gut has been shown to impact the health of your body and brain. It is possible to shift the balance towards “good” organisms by changing what you eat and keeping yourself happy and fit. Here is a useful website for tips on how to improve your microbiome
<https://www.sciencefocus.com/the-human-body/how-to-boost-your-microbiome>.

Here are some useful resources to help with eating healthily:

The British Nutrition Foundation website contains guidance on a balanced diet aligned to the NHS Eatwell campaign. Visit <https://www.nutrition.org.uk/creating-a-healthy-diet/a-healthy-balanced-diet/>

British Association for Nutritional Therapy (BANT) provides information on nutritional therapy and nutrition, how to find a registered nutritionist and how to prepare for a nutritional consultation.

It also contains a searchable database to allow you to search for local nutritionists. This is their website: bant.org.uk.

Enjoyment and distraction

Try to include at least one enjoyable activity in your list of things to do every day. Find the time to phone a friend or go out to the cinema, even if you have to leave halfway through. Be pleased with the things you accomplish. Fun and pleasure stimulate serotonin ('the happiness hormone') in our body. Enhanced serotonin levels reduce pain and improve sleep and mood.

Shift your attention onto something else so the pain is not the only thing on your mind. Get stuck into an activity that you enjoy or find stimulating. Many hobbies (like photography, painting or knitting) are possible even when your mobility is restricted.

Complementary therapies

Alternative therapies have the potential to alleviate pain in some cases. The British Acupuncture Council (BAcC) is the UK's largest self-regulatory body for the practice of traditional acupuncture. Visit their website at <https://acupuncture.org.uk>

The Complementary and Natural Healthcare Council (CNHC) provides details of complementary therapy practitioners who meet national standards of competence and practice. Visit their website at www.cnhc.org.uk.

There is a lot of publicity surrounding CBD, or cannabidiol, which is a non-psychoactive compound found in marijuana and hemp. In other words, it is the part of marijuana that does not get you high but is believed to provide a host of health-promoting benefits.

Research into CBD is still in its infancy. We are not able to recommend CBD products, but we have heard that some people find them helpful. CBD is unregulated and considered a dietary supplement, not a medication. This means that doses vary from product to product which adds confusion when the effective therapeutic dose of CBD for various conditions is unknown.

CBD can prevent insomnia. The connection between CBD and sleep dates to around 1200 AD and modern studies also show that CBD may help you fall and stay asleep. Some studies suggest that CBD helps to relieve anxiety. Studies also suggest that CBD may alleviate chronic pain and inflammation.

When it comes to CBD and pelvic pain there are many unknowns. Ultimately, more research is needed to fully understand CBD's role in pain management.

Sex and intimacy

Many women with pelvic pain experience problems with sex and intimacy. This might range from low desire, reduced arousal or even pain with sex. This can negatively impact relationships and lead to further deterioration in well-being.

It is important to communicate with your partner and let them know how you are feeling. This might mean having a difficult conversation. However, most of the time this will help your partner to understand how you are feeling and what you are experiencing so you can make a plan and move forward together.

If you think you need help to deal with problems relating to sex and intimacy you can ask your GP or specialist who can direct you towards a range of interventions. Some of these interventions may be free on the NHS.

Services that may be useful include:

Relationship therapy and counselling

Relate provides relationship counselling. It has a searchable database of local registered counsellors. Visit their website at www.relate.org.uk

Family Lives provides parenting and family support using their website, helpline and through local support. Visit their website at www.familylives.org.uk

Sex therapy

College of Sexual and Relationship Therapists are a professional body for Psychosexual and Relationship Therapists. Holds a national register of specialist therapists. Visit their website at www.cosrt.org.uk

The Institute of Psychosexual Medicine (IPM) trains doctors and related health professionals who see patients with psychosexual dysfunction presenting in their normal practice. They hold a register of trained professionals. Visit their website at www.ipm.org.uk

Pelvic physiotherapy

Your GP or specialist can refer you to a women's health physiotherapist. This is a quick pelvic relaxation video: www.youtube.com/watch?v=dtklY0Uy0Lo.

Pelvic physiotherapists are experts at working with women with pelvic pain. They will assess you and guide you on appropriate physical therapy that may help with your symptoms.

Trauma

Some women may have experienced traumatic sexual experiences, which can impact on their enjoyment of sex and even make pelvic pain worse. People deal with these experiences in different ways, if you need help working through previous sexual assault or rape, there is help available.

Yorkshire Survivor Pathways is designed to provide a comprehensive web directory of the services available in Yorkshire and Humberside to help support victims and survivors of sexual abuse.

Visit their website at www.yorkshiresurvivors.co.uk.

Ideas to help reduce pain with sex

The 'Ohnut' is an intimate wearable that allows couples to explore comfortable penetration depths.

It is a soft stretchy ring worn externally at the base of a penetrating partner (over the penis or toy). It compresses down to act like a buffer. Each set comes with four stacking rings that make it simple to incrementally adjust the depth of penetration to work out how deep feels good for you and your partner. It is available to purchase online.

Personal lubricant is a liquid or gel that can be used during sexual activity to reduce friction between body parts or a body part and a sex toy. They can increase pleasure and reduce pain. There are many options and different types work better for different purposes.

Other resources:

NHS: www.nhs.uk/live-well/healthy-body/ways-to-manage-chronic-pain/

The Pain Toolkit website helps people manage persistent pain. It includes videos on managing pain, workshop details and many other resources including a pain toolkit to download.

Visit their website at <https://www.paintoolkit.org/>

Action on Pain is a growing national charity that provides practical help and support to people living with or affected by chronic pain. The charity is run by a team of people who have direct experience of living and dealing with long-term pain conditions. Visit their website at <https://action-on-pain.co.uk>

The Pelvic Pain Support Network is an organisation that provides support, information, and advocacy for those with pelvic pain, their families, and carers.

Visit their website at www.pelvicpain.org.uk

Tell us what you think of this leaflet

We hope that you found this leaflet helpful. If you would like to tell us what you think, please contact Miss Gemma Bentham, Consultant Obstetrician and Gynaecologist, York Hospital, Wigginton Road, York, YO31 8HE or phone 01723 342515.

Teaching, training and research

Our Trust is committed to teaching, training and research to support the development of health and healthcare in our community. Healthcare students may observe consultations for this purpose. You can opt out if you do not want students to observe. We may also ask you if you would like to be involved in our research.

Patient Advice and Liaison Service (PALS)

PALS offers impartial advice and assistance to patients, their relatives, friends and carers. We can listen to feedback (positive or negative), answer questions and help resolve any concerns about Trust services.

PALS can be contacted on 01904 726262, or email yhs-tr.patientexperienceteam@nhs.net.

An answer phone is available out of hours.

Leaflets in alternative languages or formats

If you would like this information in a different format, including braille or easy read, or translated into a different language, please speak to a member of staff in the ward or department providing your care.

Patient Information Leaflets can be accessed via the Trust's Patient Information Leaflet website:
www.yorkhospitals.nhs.uk/your-visit/patient-information-leaflets/

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