

Developments in recognising chronic pelvic pain



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Living with any chronic pain imposes a heavy economic and social burden. The Pelvic Pain Support Network (PPSN) is a patient and volunteer led charity. Established in 2006, the charity supports those with undiagnosed as well as diagnosed, long-term (chronic) pelvic pain, by highlighting this much neglected area and improving access to care for patients.

What is chronic pelvic pain?

Chronic pelvic pain is defined as either intermittent or constant pain in the pelvic region lasting longer than three months. It presents in primary care as frequently as migraine or low back pain.

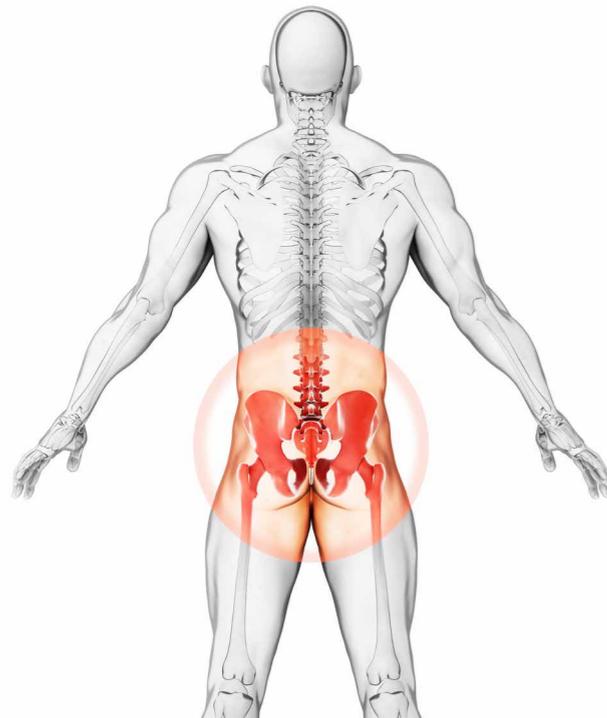
The World Health Organization (WHO) has recognised the International Classification of Diseases 11 (ICD 11) work on chronic pain, which takes effect in 2022. This means that chronic pain is now noted as requiring special consideration and treatments; chronic pain can be tracked as a diagnosis or co-diagnosis in an underlying disease, and data such as cost information, treatments, and societal impact of pain can be made more readily available.

What are the challenges for pelvic pain patients?

Nationally, patients face difficulty in being referred for help in managing their pain, despite this being their priority. Services are designed to cater for those with straightforward pelvic pain issues that can be resolved quickly by a single specialisation.

Chronic pelvic pain encompasses gynecological, urological, gastrointestinal, neurological and musculoskeletal causes and it is not unusual for more than one of these to be involved.¹ This can present a clinical challenge with regards to assessing, treating and managing symptoms as, traditionally in the UK, there has not been a multidisciplinary approach to pelvic pain.

In complex cases it may be difficult for any single speciality to decide how to progress the care of the patient necessitating referral to a regional pain management centre.² NICE recognises the benefit of pain management programmes for chronic pelvic pain.³



What is PPSN doing to improve the situation?

Within the charity, we encourage a multidisciplinary approach and work to change the traditional culture. Our advocacy role involves campaigning on behalf of pelvic pain patients through representation at conferences, meetings, workshops, policy development and events for clinicians and the public. We invite and encourage patients to participate in all aspects of our work and regard developing their skills as crucial.

We help educate both the medical profession and the public, by raising awareness in all matters relating to pelvic pain and its treatments. Patients deliver sessions on the "patient experience" for undergraduate nurses and doctors. This forms part of the chronic pain curriculum for nurses and for fourth year trainee doctors in the obstetrics and gynaecology rotation in some UK universities.

The charity was awarded first place in the category "Professional Education" for the European Civic Prize on Chronic Pain in recognition of our work "Patients as Teachers in Health Professional Education". Patients who deliver this have broader experience of treatment within and outside of the UK, elsewhere in Europe.

We have organised several workshops to encourage cooperation between clinicians and researchers from various disciplines and countries to foster a greater exchange of information and collaboration in the field of chronic pelvic pain.

We encourage research by appropriate institutions that aims to improve the quality of life of those with pelvic pain. PPSN continues to represent those with pelvic pain in many research trials and studies. Several of these have been published and some are ongoing. This involves patient input at all stages of the process from the pre funding application stage through to dissemination of the results. An example of such research is described in the accompanying article.

Information and support for those with pelvic pain and those close to them is available via our website, message board and Facebook page. Patients appreciate information that helps them to understand their pain and what they can do to help manage it. This allows them time to digest information and can facilitate shared decision making.

References

1. EAU Chronic Pelvic Pain Guideline <https://uroweb.org/guideline/chronic-pelvic-pain/>
2. The Royal College of Anaesthetists: Faculty of Pain Medicine (2015). Core Standards for Pain Management Services in the United Kingdom.
3. The National Institute for Clinical Excellence (2017). Endometriosis: diagnosis and management. NICE guideline NG73.

Read more at
pelvicpain.org.uk
@pelvicpain

New approach in research on two pelvic pain disorders

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Endometriosis and interstitial cystitis affect millions worldwide. The causes of both diseases remain unknown, there is no cure and pain frequently persists and can worsen.

Status of the conditions

The recently updated International Classification of Diseases, ICD 11 includes the category "chronic visceral pain from persistent inflammation in the pelvic region", hence recognizing the pain associated with Endometriosis and Interstitial Cystitis/Bladder Pain Syndrome (IC/BPS)¹. The public-private partnership Innovative Medicines Initiative, IMI-PainCare, aims to improve the management of chronic pain. Specifically, Chronic Pelvic Pain is the focus of their subproject TriPP (Translational Research

in Pelvic Pain) which is committed to improving the translation of laboratory and clinical findings into treatment for Endometriosis Associated Pain (EAP) and IC/BPS.

Diagnosis and treatment of endometriosis and IC/BPS

Endometriosis and IC/BPS are difficult to diagnose, with laparoscopic surgery and histology required for endometriosis diagnosis and IC/BPS being diagnosed when all other possible diseases causing bladder pain and increased urinary urgency and/or frequency are excluded. Whilst there are guidelines for treatments to improve pain symptoms, any symptom improvement is generally short-term and treatments have associated side-effects. Preclinical research in animal models for EAP and IC/BPS are at different developmental stages with a lack of consensus, which hinders the development of new medicines.

Disease understanding is essential

Currently, improving patient management is challenging because of the complexity of the disorders

and our limited understanding of them. The TriPP strategy is based on obtaining information, including biomarkers, directly from patients in order to identify the relevant biological pathways affected in these disorders. This information will be used to refine the existing preclinical models, with a particular focus on translational aspects so that they better reflect the symptoms seen in EAP and IC/BPS. One of TriPP's hypotheses is that the pain symptoms in EAP and IC/BPS are generated and maintained by mechanisms which are similar to those seen in other chronic pain conditions and that they occur alongside specific pathological lesions and symptoms. The project also aims to establish whether women with EAP and BPS can be stratified into subgroups and to explore whether these subgroups relate to treatment response.

References

1. Aziz, Q., et al., The IASP classification of chronic pain for ICD-11: chronic secondary visceral pain. *Pain*, 2019. 160(1): p. 69-76.

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IMI-PainCare TRIPP aims to provide the scientific community with better tools to both manage pain and to discover new treatments and cures for endometriosis and IC/BPS, ultimately improving the quality of life for patients. Detailed information on this consortium can be found at www.imi-paincare.eu/

Paid for by IMI - Paincare



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