

Frequently Asked Questions (FAQs) About Chronic Pelvic Pain

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Frequently Asked Questions (FAQs) About Chronic Pelvic Pain

What is chronic pelvic pain (CPP)?

Pain can be felt in many parts of the body and it can persist to become chronic or long-lasting. Chronic pelvic pain is pain that is located anywhere in the lower abdomen, pelvis, lower back or genitalia. Sometimes the pain can be felt in the upper thighs or legs. In general, pain is considered chronic if it does not respond to initial treatments, lasts longer than 3-6 months regardless of its location, and if it is associated with disability or need for medical care. The pain may come and go, or it can be constant. Sometimes chronic pelvic pain occurs on a regular cycle, such as

during menstruation or it can occur before or after walking, eating, urinating, or during sex.



How many people have CPP?

50 Million US Adults live with daily chronic pain. Within that subset, more than 19 million live with what is called 'high-impact' pain; pain severe enough to interfere with daily life or work activities. It is estimated that 1 out of 5 Americans suffers with chronic pain localized to the pelvis. Chronic pelvic pain affects primarily women; approximately 22 million women in the US. A major problem that pain sufferers face is access to care; less than 5 for every 100 people living with a chronic pain disorder have access to a healthcare provider that specializes in chronic pain. On average, persons with CPP suffer approximately 4 years before receiving care from a pain specialist.

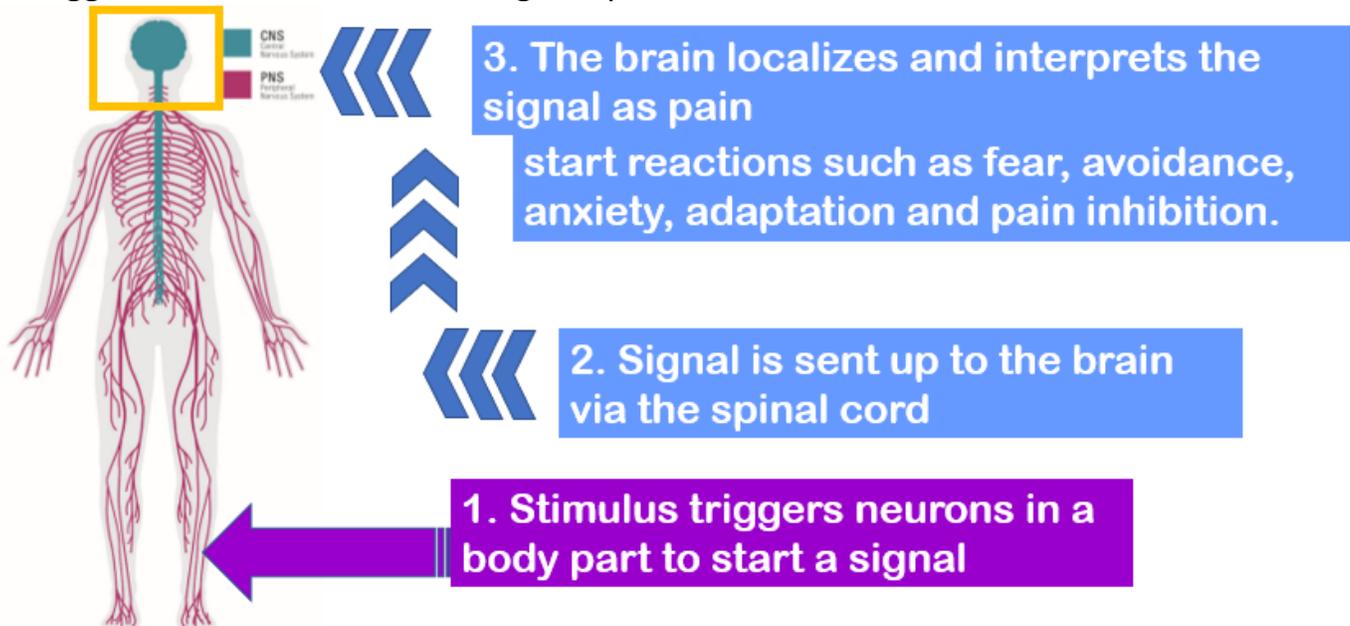
Who gets chronic pelvic pain?

Anyone, regardless of age, race, ethnicity, social and economic background can get persistent pain, however, some populations have a higher risk. For example, more than **94,000 veteran women have chronic pelvic pain**. It is estimated that 1 out of 4 veteran women seek care for CPP compared to 1 out of 6 non-veterans. CPP affects women twice as often as men. Research shows that there are some things that increase the risk of getting chronic pain including a history of military sexual trauma, anxiety, depression or PTSD, having multiple surgeries, and certain lifestyle habits such as smoking and substance abuse. Opioid use can also increase the risk of developing long-lasting pain. It is important to note that these risk factors are more prevalent in veterans, placing them at higher risk for developing chronic pelvic pain.

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How and why do we feel pain?

The human body has special cells designed to feel things around you. These cells are called **neurons** and they are located all over the body and the brain. Generally, these cells collect information whenever they are triggered by a touch, sight, or a smell. They can also be triggered by bad things such as inflammation, injury or damage caused by disease. After they are triggered, these cells send the signal up to the brain.



The brain then figures out what the signal is (so that you know whether it is a smell, sight, sound, or touch), it tells you where the signal is coming from (like your abdomen, back or legs) and it tells you whether the signal is pleasant or painful. It is important to understand that the signal does not feel as painful until it reaches the brain. After the brain interprets a signal as painful, then the brain starts other reactions to the pain such as fear, avoidance of the painful stimulus, anxiety, and eventually getting used to the pain. Many things determine how your brain reacts to the pain including your past experiences, expectations and your mood. The brain also has the ability to control the pain so that you eventually get used to it and actually feel less pain.

How does chronic pain develop?

In most cases pain develops from obvious damage to the flesh like a broken bone, a burn, or an infection. This type of pain usually goes away as the damage heals. But sometimes the flesh does not heal, and the pain can go on a long-time and become chronic. Sometimes the injury heals, but the neurons (the cells that allow you to feel things) continue to send signals to the brain, this too can turn into chronic pain. At other times, the brain can malfunction so that it overinterprets the pain signal, or it cannot tell where the signal is coming from, or it cannot

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control the emotions that are started by the pain, or it cannot control the level of pain. If any of these things happen, then a person can start feeling pain when there is no obvious damage, or they can feel pain that is more painful than expected. When the brain does not respond to the signal properly, people can also start feeling pain in multiple areas of the body or experience a lot of difficult emotions such as worrying, sadness, anger and sleep problems. All of these problems with the brain can become chronic pain. Also, when persons with long-lasting pain start showing these signs, it is known as **Central Sensitization**.

What causes CPP?

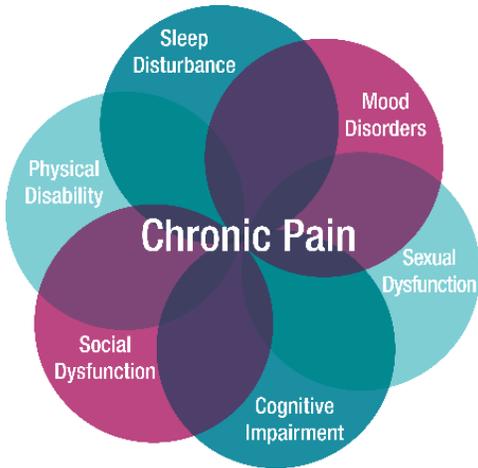
Many conditions can cause chronic pelvic pain including: Irritable Bowel Syndrome (IBS), Interstitial Cystitis or Bladder Pain Syndrome, chronic prostatitis, Low Back Pain, Myofascial or Musculoskeletal pain (pain from the pelvic muscles and bones), Neuralgias (pain from neurons such as Pudendal Neuralgia and Diabetic Neuropathy). In other cases, chronic pelvic pain can be caused by trauma, injury or surgery. In women, chronic pelvic pain can also be caused by conditions such as Endometriosis, Adenomyosis, pelvic masses or ovarian cysts, pelvic infections, severe menstrual pain and genital conditions such as vulvodynia. Although Endometriosis affects 8 out of 100 women, and is a common cause of chronic pelvic pain, it is important to note that less than 1 out of 5 of persons with CPP have only a gynecologic cause for their pain. In fact, twice as many persons with CPP (2 out of 5) have more than one pelvic pain condition. Many have no abnormality on [laparoscopy](#) (a surgical procedure in which a small camera is inserted into the abdomen to find what is causing the pain).

Can other conditions worsen CPP?

There are several other pain conditions that may worsen chronic pelvic pain such as chronic migraines, tension headaches, Fibromyalgia, chronic fatigue syndrome and temporomandibular joint pain. In fact, 20%, or 1 out of five people living with chronic pelvic pain have more than one pain condition. As the number of pain conditions increases so does the level of pain, disability and whole-body dysfunction that a person experiences.

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What is the long-term result of living with untreated chronic pelvic pain?

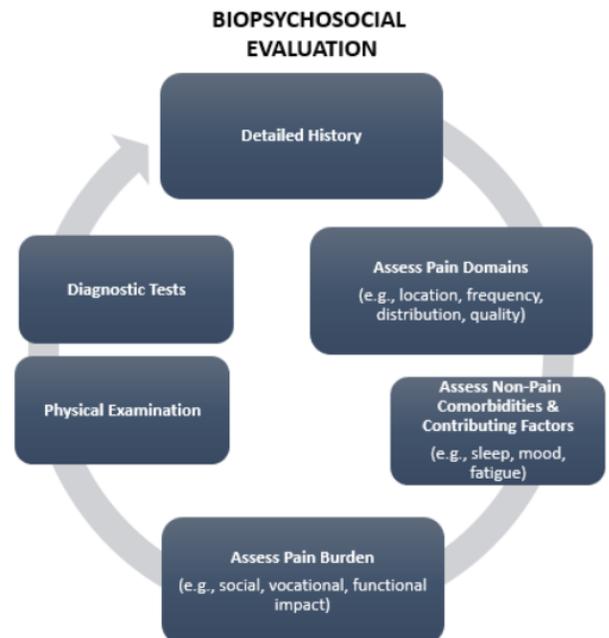


Research shows that living with untreated chronic pelvic pain can lead to problems sleeping and feeling tired. It can also cause problems with memory, learning or concentration and trouble with physical activity, social, personal and sexual relationships. Persons who live with this type of pain many times feel alone and are often dismissed by their peers and healthcare providers. Nearly half of chronic pelvic pain sufferers may also have severe emotional problems such as anxiety, depression and worsening PTSD. Sometimes, medications used to treat chronic pain may also lead to side effects such as worsening depression, anxiety and sexual

problems, and this may lead to a cycle of worsening disability.

How is chronic pelvic pain diagnosed?

Your health care provider will do what is called a **biopsychosocial** assessment, where you will first be asked about various factors that may affect your pain including your medical, surgical, psychological and social history. Your provider will also want a detailed description of the medications and previous treatments you've tried, including previous surgeries. Be prepared to answer intimate questions about your mood, sleep, relationships with your peers, your sexual history and general questions about your support and work environment. This type of assessment can be quite lengthy and require several visits. Some providers use surveys to collect some of this important information. When this is complete, you will likely undergo a detailed physical exam including a pelvic examination. Your provider will assess your internal organs, your muscular and bony structures and may even perform a neurologic exam to test your pain sensitivity.

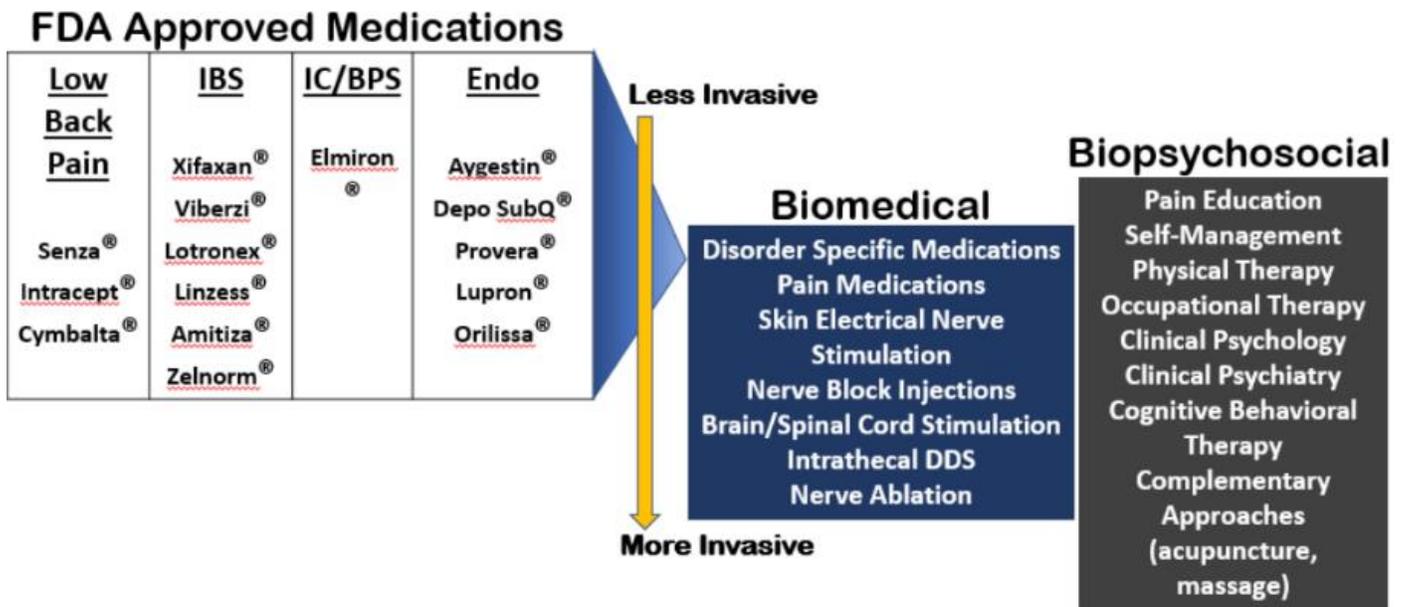


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What tests can be used to identify causes chronic pelvic pain?

Tests that may be recommended by your health care provider include a urine screen, a pregnancy test, a genital swab to test for infections, a pelvic ultrasound or CT or MRI to image the internal pelvic organs such as the bowel, bladder, kidneys, uterus, and ovaries. It also may be necessary to see other specialists to find out the cause of your pain, such as a gynecologist (a provider who specializes in women’s health) gastroenterologist (a provider who focuses on digestive problems) or urogynecologist (a provider specializing in urinary and related problems). Sometimes, specialists recommend additional tests such as a [colonoscopy](#), [cystoscopy](#), or even [laparoscopy](#).

What therapies are recommended to relieve chronic pelvic pain?



Many treatments are available to manage *specific* disorders that cause chronic pelvic pain. For example, there are now several FDA approved medications chronic low back pain, IBS, IC, and Endometriosis. However, regardless of the original cause of the pain, there are additional ways of controlling pain, ranging from less invasive such as pain-relieving medications, physical, psychological nutritional therapies, anesthetic injections and nerve blocks to more invasive methods such as spinal cord stimulators and surgery.

It is essential to identify *all* factors and health disorders that play a role in your pain and develop a comprehensive treatment plan that goes beyond medications. Similarly, related conditions, such as sleep, fatigue, cognitive difficulties and mood disorders, can be managed with various treatment options, and are important to address. Everyone is unique and

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responds differently to treatments, but usually a combination of drug and non-drug treatments is most effective in reducing the severity of pain and improving quality of life, this is called **multi-modal** and **interdisciplinary therapy**. This type of pain management requires careful discussion with your health care provider. It can take some time and trial-and-error to find treatments that work best for you without producing negative side effects. Nonetheless, a **mind-body** approach, combining therapies from more than one clinical discipline, through **shared-decision making** between you and your provider, has been proven to reduce pain severity, increase function and improve overall quality of life.

What should you do before you go see a provider for chronic pelvic pain?

Providing a detailed history will help your provider make the best therapy recommendations. Before your visit, spend some time detailing your pain journey and your treatment goals which may include less pain, improved activity (including physical and sexual activity), improved bowel and bladder function, etc. Completing a [Personal Health History](#) will avoid missing important elements of your history and will help communication with your provider. Some providers use surveys or questionnaires to assess your health history; when you make an appointment ask if there are any forms and complete them fully before your appointment. If you have medical records at home, such as surgery reports or results from other tests, bring copies to your appointment. In addition, make sure you have the names and contact information of the other health care providers that are currently treating you.

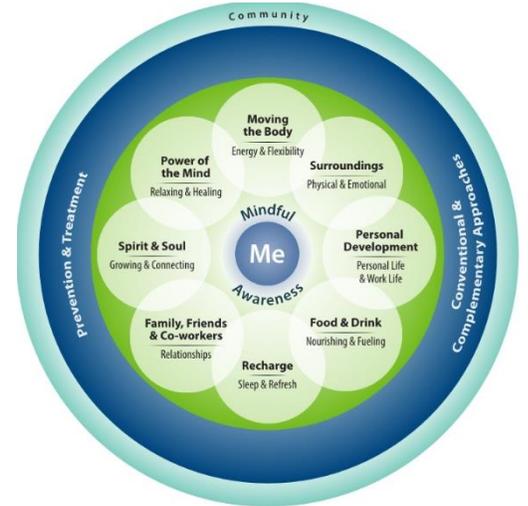
What should you expect from your provider?

Chronic pain therapy requires you to have different expectations from your health care team; expect needing multiple visit to establish what treatment path is best for you. Also, because chronic pain pathways are established in the brain, diagnostic tests are often negative, but that does not mean you do not have pain. Conversely, when a health care provider recommends psychological interventions to manage pain, it does not mean that they do not believe or doubt your pain. In fact, you should expect a shift from treatment recommendations using a single pharmacologic intervention to multi-modal therapy that uses several interventions at once that are tailored to your needs and goals. Remember, this takes time and trying things out. Also, each person with pain is unique, so you should not expect to have the same experience as anyone else.

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What else can you do on your own to manage your pain?

Before you see a health care provider write down how you feel pain and be ready to discuss the number of pain sites, locations, what makes the pain worse or better, what the pain does to your life (including your work, sleep, and relationships) and previous treatments you have tried. Share this information with your provider, and after your evaluation is complete (remember, this may take more than one visit) discuss therapies that target all aspects of your pain and disability. Remember, the brain is the most important controller of pain and many therapies that target brain function can help lower pain. **Staying physically active and finding positive ways to manage pain is important since inactivity worsens pain.** Overall, your participation in the healing process is necessary, that is, self-education and self-management are key to improvement. Below you will find a list of resources that will help you in your healing journey.



Glossary of terms

Colonoscopy: An exam of the entire colon using a small, lighted instrument.

Cystoscopy: A test in which the inside of the urethra and bladder are examined.

Laparoscopy: A surgical procedure in which a slender, light-transmitting instrument, the laparoscope, is used to view the pelvic organs or perform surgery.

Ultrasound: A test in which sound waves are used to examine internal structures.

Resources for management of chronic pelvic pain

VA Whole Health: <https://www.va.gov/WHOLEHEALTH/veteran-resources/whole-health-basics.asp>

International Pelvic Pain Society Patient Education Pamphlets:

https://www.pelvicpain.org/IPPS/Patients/Patient_Handouts/IPPS/Content/Professional/Patient_Handouts.aspx?hkey=cffd598e-5453-4b3f-9170-457c59266b50

Chronic Pain Research Alliance Patient Guide: <http://www.chronicpainresearch.org/Resources>