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## Chronic Pelvic Pain

### What is Chronic Pelvic Pain (CPP)?

CPP is any pelvic pain that lasts for more than six months and occurs in the pelvis or lower abdomen. Sometimes the cause of the pain is not obvious. At other times, the problem, which originally caused the pain, has lessened or even gone away completely, but the pain continues.



Chronic pelvic pain is one of the most common health care problems in our society. It is estimated that 25 million women suffer with chronic pelvic pain. Approximately 25% of women with CPP may spend 2-3 days in bed each month. More than half of the women with CPP must cut down on their daily activities 1 or more days a month and 90% have pain with intercourse (sex). Almost half of the women with CPP feel sad or depressed some of the time. Although CPP is more prevalent in women, it can also occur in men where it is often known as chronic abacterial prostatitis. In men, the pain can manifest in the perineum, rectum, prostate, penis, testicles and abdomen. Chronic pelvic pain impacts people across the gender spectrum including transgender, LGBTQ and gender non-conforming. For many transgender and gender non-conforming people, healthcare is not easily accessible. CPP is also poorly studied in this patient population.

### What is the difference between “acute” and “chronic” pain?

Acute pain is the pain, which occurs when the body is injured, as in the case of infection of the appendix (appendicitis). There is an obvious cause for the pain. Chronic pain is very different. The original cause of the pain may be gone. This is caused by changes in the muscles, nervous system or other tissues. The pain itself becomes the disease.

### What is “Chronic Pelvic Pain Syndrome”?

When constant, strong pain continues for a long period of time, it can become physically and mentally exhausting. To cope with the pain, the people may make emotional and behavioral changes. When pain has continued for so long and such an extent that the person in pain is changing emotionally and behaving differently to cope with it, this is known as “Chronic Pelvic Pain Syndrome”.

People with this condition will have the following:

- Pain present for 6 or more months “
- Conventional treatments have not relieved the pain or have given only small relief
- The pain is stronger than would be expected from the injury/surgery/condition which initially caused the pain
- Increasingly less and less physical activity
- Changes in how the person relates in their usual social roles as partners, employee, etc.



CPP is a combination of physical symptoms (pain, trouble sleeping, and loss of appetite), psychological symptoms (depression), and changes in behavior (change in relationships due to the physical and psychological problems). It is not “all in your head”!

## Can CPP affect other parts of my body?

A person who has had CPP long-term may notice symptoms in other muscles and organs of the body as well. It is common for pain to cause muscle tension. CPP sufferers may notice lasting changes in the muscles that affect the bladder and the bowel. Patients also may notice pain involving the back and legs due to muscle and nerve involvement. Once these problems have started, they may become more painful and troublesome than the pelvic pain, which started them. Health care providers who specialize in treating chronic pelvic pain will examine all your organ systems (e.g. bladder bowel), not just your reproductive organs (e.g. uterus, ovaries, penis or scrotum).

## How do I feel pain?

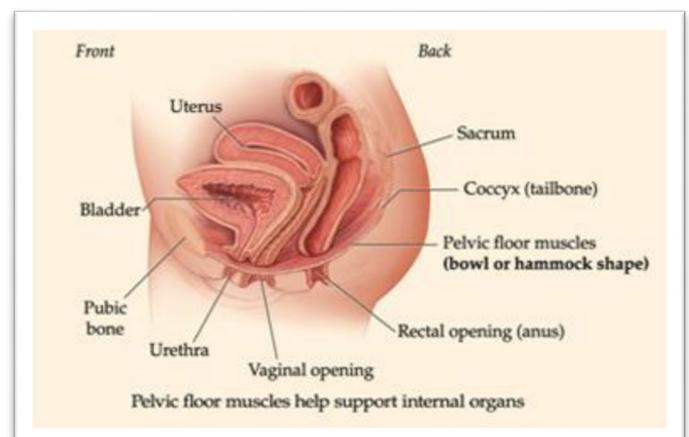
Injured body tissues send signals through special nerve cells to your spinal cord. The spinal cord acts like a gate. It can let the signals pass to the brain, stop the signals or change them, making them stronger or weaker. What action the spinal cord takes is influenced by other nerve messages coming in at the same time and by signals coming down from the brain. So, how you perceive pain is affected by your mood, by the environment and by other processes happening in your body at the time.

When a person has chronic, long-lasting pain, the spinal cord ‘gate’ may be damaged. This may cause the ‘gate’ to remain open even after the injured tissue is healing. When this happens, the pain remains in spite of treating the original cause.

## What are the characteristics of chronic pain?

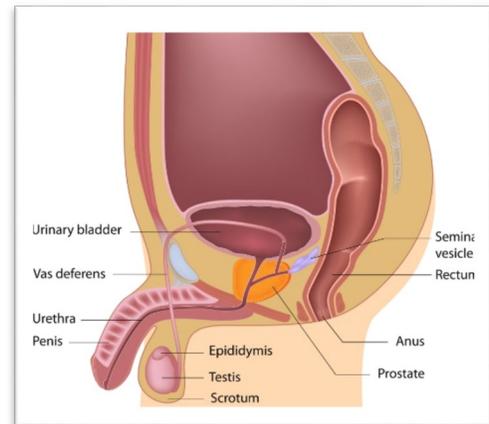
There are four main factors:

- 1) **Pathology at the site of origin.** There is or was an injury (pathology) at the place (site of origin) where the pain first started. This injury might be infection, trauma, a tumor, or adhesions in a specific organ such as the bladder or bowel. Persons with female reproductive organs may have uterine or pelvic conditions such as endometriosis, ovarian cysts, whereas those with male reproductive organs may have prostate masses or infections.



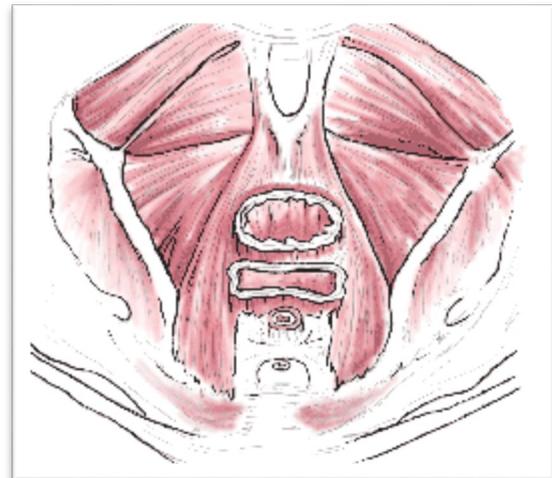
Female pelvic organs

2) **Referred Pain.** Your body has two types of nerves. **Visceral** nerves carry impulses from the organs and structures within your abdomen and chest (stomach, intestines, lungs, heart etc.). **Somatic** nerves bring messages from the skin and muscles. Both types of nerves travel to the same sites on the spinal cord. When your visceral nerves are stimulated for long periods with chronic, ongoing pain, some of this stimulation may spill over into the somatic nerves, which then carry the pain back to the muscles and skin. In CPP, the somatic nerves may carry the pain back to your pelvic and abdominal muscles and skin. That means that your pain may start in your bladder and spread to your skin and muscles, or the other way around.



Male pelvic organs

3) **Trigger points** are specific areas of tenderness occurring in the muscle wall of the abdomen. Trigger points may start out as just one symptom of your pelvic pain or they may be the major source of pain for you. For this reason, treating the trigger points, for some people, may significantly reduce the pain. For others, the original source of injury *as well as* the trigger points must be treated.



Female pelvic floor muscles

4) **Action of the Brain.** Your brain influences your emotions and behavior. It also interacts with your spinal cord and affects how you feel the visceral and referred pain. For instance, if you are depressed, your brain will allow more pain signals to cross the gates of the spinal cord, and you will feel more pain. This influence or modulation by the brain must also be treated. Treatment can include psychological counseling, physical therapy and medications.

It is important to remember that all of these 4 levels of pain must be treated together for CPP therapy to be successful.

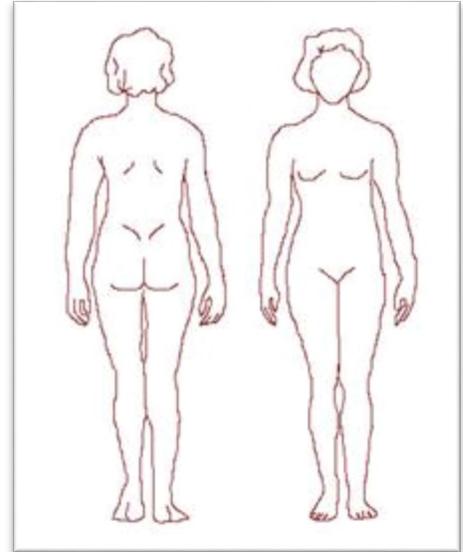
## How will my health care provider diagnose CPP?

Your health care provider will take a thorough history of your problem. It is very important to give your physician a detailed and accurate description of the problem. The health care provider will also do a physical examination. After this, the health care provider will be able to determine what lab tests and procedures might be needed to find the reasons for your pain.

There are a number of things you can do to help your health care provider diagnose and treat you:

- Get copies of your medical records, including health care provider visits, lab tests, x-rays and surgical testing.
- If you have had surgeries, records of the surgical treatments, including videotapes are very helpful.
- Carefully fill out the health care provider's questionnaire. Take your time and try to remember all the details and the order in which they happened. Just filling out the questionnaire may help you remember details you had forgotten. Also, it may be easier to write out personal information that is difficult or embarrassing to talk about. Remember that the more information you give the health care provider, the easier it will be for them to help you. Factors which may be very important in your care are

- How and when did your pain begin?
- What actions or activities make it better or worse?
- Does it vary based on time of day, week or month?
- How does your menstrual cycle affect the pain?
- How does the pain affect your sleep?
- Has the pain spread since it began?
- Do you notice abnormal skin sensations (pain, itching, burning), muscle or joint pain or back pain?
- Do you have pain with urination (peeing), constipation, diarrhea or other problems with your bowels?
- Has the pain caused emotional changes like anxiety or depression?
- What have you done to relieve the pain? What has worked? What has not worked?
- What medical treatments have you had? Have they helped?
- What medications have you used in the past? What medications are you taking now?
- What do you think is causing your pain?
- What concerns you most about your pain?



Your health care provider will do a very thorough physical exam. Remember that your pelvis is very important, not only for containing your organs, but also because it provides the support for your upper body and connects the upper body to the lower body. For these reasons, not only will the pelvic organs, vagina and rectum be examined, but also posture, gait, back, abdomen, legs and thighs. Special attention will be given to the pelvic muscles as well as to any changes in skin sensation, numbness or tenderness. Your health care provider will also check closely for trigger points. If needed, a close examination of the vagina and also the labia (lips of the vagina) will be done. The provider may also do a rectal examination but only if needed. During these examinations, you may be asked at times to tense and relax specific muscles. Throughout all this, your health care provider will be looking for clues of damage or disease, which might have started the pain, and clues to which nerves are contributing to the pain.

## What factors will my health care provider consider when deciding how to help me?

Your health care provider will consider several factors in deciding how best to treat your pain. Sometimes, when you've had pain for a long time it starts to feel like the pain is all in your mind! Pain is mediated by the nervous system, which includes the body and the brain. The pain is not all in your body, but it is not all in your head either! For a treatment to be effective, the treatment needs to treat the body and the mind. Usually, CPP is not caused by a single problem but by a number of problems interacting together. This means that many times there is no single "treatment" for CPP. You may need several treatments for all the problems.

It is impossible to tell how much each individual pain factor adds to the whole problem. In fact, whatever caused your pain in the first place may become only a minor factor while the chronic pain is caused by secondary factors. Therefore, ALL factors must be treated, not just the ones that "seem" the most important.

## How soon will I start to feel better?

It may take a long time before you start feeling better, even though your health care provider is trying to provide you with relief as quickly as possible. It took a long time for your pain to become bad and may take weeks or months for it to improve. During your treatment, as you are slowly improving, try to remain calm and patient and keep a positive attitude.

## Will I receive pain medication?

In the early stages of your treatment, you may be given pain medication. The therapies for treatment of CPP take time to work and medication will keep you comfortable until they can take effect. However, remember that the pain medication is just a temporary treatment for the symptoms (the pain you feel) but the therapies you are using are the cure for the problem. Pain medications may not take all of your pain away but may make your symptoms more bearable.

All medications can have side effects, especially opioids which are actually not recommended for the long-term treatment of chronic pain. Your health care provider will probably prefer to try non-narcotic pain relievers first to avoid potential drug side effects.

You may be given a combination of medications instead of one. Often medications complement each other and are more effective if used in combination. You may get the most relief using some medications for pain and others for mood such as antidepressants.

Taking medication every time you feel pain can make you dependent on medication. Taking medication at fixed times rather than each time you have pain has been found to be more effective in pain control. Your health care provider will give you prescriptions for a fixed amount of pain medication and you will be told to take a certain dose of medicine on a regular schedule at set times.



If you find that over time the medication is relieving your pain less and less, your body may be developing a tolerance for the pain medication. Talk to your health care provider about how effective your medication is at each visit. If necessary, call and make an appointment to talk with your health care provider. Changing pain medication is not something your physician can do easily do on the basis of a phone conversation.

If you and your health care provider find it necessary to use strong opioids to control your pain, it is your responsibility to use them safely and correctly. If your prescription is lost or stolen, it will not be replaced. Refills will not be given. If your health care provider finds you have been receiving prescriptions for opioids from other physicians as well during your care without permission from the health care provider, he/she/they may no longer provide care to you.

### What about my muscle aches and pains?

Treating any problems with your musculoskeletal system is an important part of your care. A physical therapist may examine and evaluate your posture, gait (how you walk), your abdomen, pelvis and legs. The therapist will do various examinations to look for abnormalities and to find muscle strength, tenderness, length and flexibility. They will also determine your “trigger points” or areas where your muscles are especially tender. You will then receive a program of physical therapy using many different techniques to help you to develop healthier, stronger muscles. You may learn special exercises for specific muscles or work with special equipment such as ultrasound or muscle stimulators. You will also learn relaxation and breathing techniques. The physical therapist will work closely with your health care provider to coordinate a program of exercises and pain medications by mouth and/or injection as needed.



### Will I be treated for emotional pain?

Chronic pain affects all aspects of your physical and emotional life and may cause anxiety, depression, sleep difficulties, sexual dysfunction and problems with your work and home life. To provide the best treatment, your health care provider must address not only the cause of the pain and pain relief, but also all the other problems it has caused. Several different therapies will be used to help you overcome these common problems in chronic pelvic pain syndrome. Learning to change the behaviors that contribute to your pain will relieve anxiety and depression and increase the enjoyment of life.

The pain you suffer also affects your family. They need to receive education about how your pain affects them and how their reactions to your pain affect you. Teaching your support system the nature of what you are going through including the symptoms, causes and many different types of treatments will help them support you in your recovery.

### What about surgical treatments?

Depending on your individual circumstances, your health care provider may decide to do surgery to determine the cause(s) of your pain and possibly to treat them as well. If you have conditions such as pudendal neuralgia, endometriosis, surgery may be helpful. However, it is important to remember that in persons who

have CPP, surgery may provide a lot, some or no relief, depending on other factors that may affect pain but are not necessarily amendable to surgery.

### **So...what can I expect from treatment for CPP?**

First off, you need to be realistic in your expectations and hopes for treatment. You should share your expectations and experiences with your health care provider and you should be part of the decision-making process when selecting treatment. However, it is important to remember that some CPP can never be completely cured and instead your provider may focus on improvements in quality of life and function instead of pain. This may involve learning resilience and how to cope with pain flares.

Don't expect instant results. Be patient with your treatment; follow all your health care provider's instructions. Treatments may take up to 3-6 months to work, so continue to follow instructions even if you don't see results right away. During your treatment and therapies, you will have set appointments with your health care provider and therapist rather than just coming in when the pain is particularly bad. You may start with weekly or monthly visits. You and your health care provider will decide whether these should be more or less frequent based on your progress. Successful treatment means decreasing your pain to a low level so that you can enjoy doing the things you want to do again.

