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CHRONIC PELVIC PAIN (CPP)

What is Chronic Pelvic Pain?

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 two to three days in bed each month. More than half of the women with CPP must cut down on their daily activities one or more days a month and 90% have pain with penetration (e.g., intercourse or sex, tampon usage, etc.). 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, penile pain or testicular pain. In men, the pain can manifest in the perineum (area between the testicles and anus), rectum, prostate, penis, testicles, low back 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) or a ruptured ovarian cyst or tubal pregnancy. There is an obvious cause for the pain. Chronic pain is very different. The original cause of the pain may be gone. Changes occur in the muscles, nervous system or other tissues to perpetuate the pain signals, and the pain itself becomes the disease.

What is “Chronic Pelvic Pain Syndrome?”

When constant, strong pain continues for an extended period of time, it can become physically and mentally exhausting. When pain has continued for so long and to 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, infection, or condition which initially caused the pain.
- Increasingly less physical activity tolerance may be replaced by lower quality of life.
- Changes in how the person relates to their usual social roles as partners, employees, etc.
- Psychological symptoms such as anxiety, feelings of isolation and depression may be present.
- Other symptoms such as poor sleep, fatigue, appetite or libido changes, pain in other regions of the body may also present.

CPP is a combination of physical symptoms (pain, trouble sleeping, fatigue, and loss of appetite, lower libido), psychological symptoms (depression and anxiety), and changes in behavior (change in relationships due to the physical and psychological problems).

Can CPP affect other parts of my body?

A person who has had CPP long-term may develop symptoms in other organs and tissues including muscles, genitals, bladder, and bowel. It is common for pain to cause tight, tender muscles throughout the body, extending from the pelvic and abdominal region up the spine into the chest, neck, cervical, and even TMJ regions due to holding tension in the body. CPP sufferers may notice lasting changes in the muscles that affect the vagina, bladder and bowel. Patients also may notice pain involving the back and legs or abdominal wall due to muscle and nerve compression/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, for example, cyclically changing estrogen levels as with ovulation, or uterine production of pain producing chemicals called prostaglandins during the premenstrual or menstrual phase or with menstrual bleeding. Pain receptors are sensitive to estrogen and prostaglandins, and so there may be greater pain during the days during certain parts of the menstrual cycle. This can lead to frustration to both you and those individuals who make up your support structure if there is not a general understanding as to possibly why your pain is up and down when you are making efforts to help yourself.

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 despite treating the original cause. As other pelvic organs become painful or surrounding muscles become tense the original pain is amplified or increased.

What are the characteristics of chronic pain?

There are five 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, inflammation, trauma, or a tumor, in a specific organ such as the reproductive organs, vagina, bladder or bowel or even a muscle or nerve injury related to exercise or trauma. Persons with female reproductive organs may have uterine or pelvic conditions such as endometriosis, ovarian cysts, while those with male reproductive organs may have prostate masses or infections.

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 in the spinal cord. When your visceral nerves are stimulated for prolonged 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 uterus or prostate or bladder and spread to your skin and muscles, or the other way around.

3) Trigger points are specific areas of tenderness occurring in the muscle wall of the abdomen or pelvic floor. Trigger points are certain points on a muscle that hold tension and have decreased blood flow within that specific tissue itself. 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.

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. Long standing pain can leave the nervous system more sensitive to pain. This influence or modulation by the brain must also be treated. Treatment can include psychological therapies, physical therapy and medications.

5) Fascial restrictions. Fascia is a soft tissue that creates a 3-dimensional network throughout the entire body, surrounding and supporting organs, muscles, and every single cell within these structures, including vessels, nerves and even hard structures such as bone. Restrictions in the fascia develop over the years from a multitude of factors, long term stress, trauma, injury, disease, inflammation, as well as emotionally charged circumstances, etc. Over time, these restrictions, if left unaddressed, remain and their effects can multiply through the years as additional restrictions are added. Often, fascial restrictions play a significant role in chronic pain.

It is important to remember that all of these five 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 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 along with operative and pathology reports of any tissue removed, including videotapes would be 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 especially 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?
 - How has the pain spread or changed since it began?
 - Do you notice abnormal skin sensations (pain, itching, burning), muscle or joint pain or back pain?
 - Do you have painful or frequent urination (peeing), constipation, diarrhea or other problems with your bowels?
 - Does the pain worsen with sexual activity including masturbation or orgasm?
 - 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 doses were used and why were they stopped? What medications including doses 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 important, not only for holding 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 or nerve entrapment. A close examination of

the vagina and the labia (lips of the vagina) will be done. The provider may also do a rectal examination 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 muscles and 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. Pain is mediated by the nervous system, which includes the body and the brain. Pain is a complex information reporting system where the brain is reporting a problem somewhere in your body. For a treatment to be effective, the treatment needs to treat the body, the nervous system and the mind. Usually, CPP is not caused by a single problem but by a number of problems interacting together. For example, you may have a pain severity of 9 out of 10, and 3/10 might be due to endometriosis lesions, 3/10 due to muscle trigger points, 2/10 due to bladder pain and 1/10 due to depression. This means that many times there is no single "treatment" for CPP. You may need several different treatments to address all the causes.

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 understand that your healing is a process, just as it was a process to get where you are. You may not have even known anything was happening in your body over years of time, especially if there was a specific event that seemed to trigger the start of your pain. It is helpful to remain open to learning new and different modalities as you are introduced to them.

If you take part in physical therapy, you may initially feel worse, but it is typical that you should feel some improvement from your baseline pain levels within 3-5 sessions. This is a sign that continued therapy will contribute to continued improvements. It is important to recognize that even in the specific modality of physical therapy, and massage therapy, there is a wide variety of diverse training and each practitioner brings a unique set of skills. You may need to try a few different practitioners to help with certain aspects of your condition or to find someone whose specific skills match your specific needs. Journaling can be quite helpful to look back and see where you were months prior. When pain continues over an extended length of time, it is easy to forget or not notice progress. Anything that you can do to help yourself remain calm, patient, and keeping a positive attitude will help to keep your nervous system calm, understanding that this can often be a challenge when experiencing pain that is chronic in nature.

Will I receive pain medication?

In the initial 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 your pain away but may make your symptoms more bearable.

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

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 that alter nerve transmission of pain signals, such as antidepressants and anticonvulsants.

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 medications (such as anti-inflammatories, antidepressants, anticonvulsants, muscle relaxants, hormonal therapies) are less effective in relieving your pain, then 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 provider. Changing medication is not something your physician can do easily based on a phone conversation.

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 spine, abdomen, pelvis and legs. The therapist will do various examinations to look for abnormalities and to find muscle strength, tenderness, length differences and flexibility. They will also determine your "trigger points" or areas where your muscles are especially tender and areas where you have fascial restrictions throughout your body. You will then receive a program of physical therapy using many different techniques to help you to develop healthier, stronger muscles. You may receive manual (hands on) therapies that address your unique restrictions, 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 mind body 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. Learning to address the emotional and traumatic contributors of your pain can also help to alleviate the anxiety and depression that result from the stress of poorly understood and unrelieved chronic pain. Also, creating a framework around which to understand or actively position your pain, can help you to manage it when it remains as part of your daily experience.

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

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

There is no simple answer, and certainly not a quick path to relief of chronic pain. Expectations and goals are best when there is a level of optimism and an understanding that goal achievement is based on many things, not only your active participation in your care, but also the presence of ongoing stressors in your life, and possibly some factors that lie outside of your control. These factors have a substantial impact on your recovery road & teasing them out can also be a challenge. 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 understand that some CPP can never be completely cured and instead your provider may focus on improvements in quality of life and function. This may involve learning resilience and how to cope with and manage pain flares.

Don't expect instant results. You can expect your practitioners to be on your team. You can expect them to hear you. It is important that you be an active part of your treatment team, taking responsibility for what you need to do and what you bring to the table, as it relates to managing what you can control in your life! And it is important that you trust yourself and your intuition in finding and building your health care team.

If you join social media groups of people with similar pain situations, be mindful that in these spaces, it is easy to fall into comparisons which can lead to heightened emotions which may worsen your pain. These groups have a purpose and can have benefits, but they also can take you down a rabbit hole that is not helpful or supportive of your mental and emotional needs. If you need a support system online to find resources, then obtain the resources, and maybe leave, but in the very least, be mindful of the rabbit hole!

Be patient with your treatment; follow your health care provider's instructions. Treatments may take up to 3-6 months to work, sometimes longer, so continue to follow instructions even if you don't see results right away. It often helps to focus on small improvements which build over time.

During your treatment and therapies, you will have set appointments with your healthcare 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.

For more information about other chronic pelvic pain syndromes visit:

International Pelvic Pain Society

www.pelvicpain.org/public

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