



THE INTERNATIONAL
PELVIC PAIN
SOCIETY, INC.

I P P S



Patient Education
B r o c h u r e

CHRONIC PELVIC PAIN

What Is Chronic Pelvic Pain (CPP)?



CPP is one of the most common and disabling medical problems. Twenty-five percent 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 intercourse (sex). Almost half of the women with CPP feel sad or depressed some of the time. Men also suffer from CPP and can experience similar lifestyle limitations. Despite all the suffering chronic pain causes, doctors are of-

ten not able to come up with a diagnosis or recommend effective treatments.

CPP is any pelvic pain that lasts for more than six months. Many times, the problem that originally caused the pain has lessened or even gone away completely, but the pain continues. This makes it much more difficult for a doctor to find the cause of the pain and to provide treatment. The pain may be in the lower abdomen, the vulva/vagina, the perineum, the anus, or the tailbone. Males can have pain in the lower abdomen, perineum, penis, testes and anus, or tailbone. In both women and men, low back pain often occurs. Bladder, bowel, sexual pains, and changes in function of these organs are common.



What Is The Difference Between “Acute” And “Chronic” Pain?

Acute pain is the pain that 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. New “pain generators” develop in surrounding tissues, such as muscles and connective tissue. Nerves transmitting the sensations from the painful areas often become excessively sensitive. This is caused by changes in the nervous system, muscles, soft tissue, and sometimes other organs in the pelvis. The chronic pain itself has now become 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, an individual may alter her or his emotional and behavioral responses. 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”.

Women and men with this condition will often have experienced the following:

- Pain present for six months or more.
- 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.
- Difficulty sleeping or sleeping too much, decreased appetite, “slow motion” body movements and reactions, and other symptoms of depression, including feeling blue or tearfulness.
- Anxiety and helplessness commonly occur.
- Increasingly less physical activity.
- Changes in how she/he relates in their usual roles as spouse, parent, grandparent, and employee.

CPP is a combination of physical symptoms:

- ✓ pain,
- ✓ trouble sleeping, and
- ✓ loss of appetite.

Psychological symptoms:

- ✓ depression, and
- ✓ anxiety.

And changes in behavior:

- ✓ change in relationships due to the physical and psychological problems.



It is not “all in your head,” but your pelvis and nervous system are connected, and without a brain and spinal cord (central nervous system) you could not experience pain!

Can CPP Affect Other Parts Of My Body?

An individual suffering from CPP may notice that they begin to have symptoms in other areas of the body as well, including muscles and other organs. It is common for pain to cause muscle tension.

CPP sufferers may notice lasting changes in the muscles of the pelvis and even the tissue and skin of the pelvis. Tension in the pelvic muscles can affect the bladder and the bowel. Patients may also 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 that started them. Doctors who specialize in treating CPP will examine all of your tissues and organ systems, not just your reproductive organs.

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, the environment, and other processes happening in your body at this time.

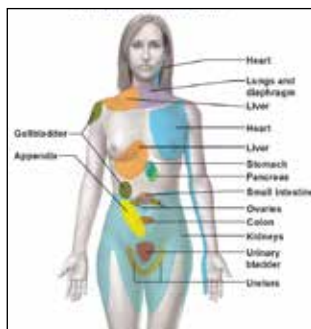
When a person has chronic, long-lasting pain, the spinal cord gate may be damaged. This may cause the gate to remain open even after the injured tissue is healing. When this happens, the pain remains in spite of treating the original cause.

What Are The Characteristics Of Chronic Pain?

There are 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 endometriosis, ovarian cysts, pain from the bowel, bladder infection, or adhesions (scar tissue from surgery). The pathology may also be an injury to a nerve in the abdominal wall, pelvis or pelvic floor, or genital area.



What about Male Pelvic Pain?

Guys suffer similar pain issues but have the pains in different anatomy. The male does not worry about endometriosis and/or female organ issues. However, his pain can be extremely severe. Pain in the perineum (between the anus and scrotal sac) is often confused with a prostate infection. Pain in the urethra or bladder may be erroneously treated as a bladder infection or sexually transmitted disease. Testicular pain may be treated as epididymitis. Some men have had varicose vein surgeries or even removal of the testicle without pain relief. Often these men are found to have abnormalities of the pelvic nerves, called the pudendal nerves. This type of nerve pain can affect women as well. Typically those with pudendal neuropathy were active in high school sports and later were very active exercisers. At sometime, a fall onto the tailbone/buttocks caused their pains. Another "at risk"

group are accountants, computer programmers, etc., who sit at their jobs for years. For women, pregnancy and childbirth or pelvic surgeries can be the cause.



2. Referred Pain and Up-regulation of Nerve Firing

Your body has two types of nerves: (1.) Visceral nerves carry impulses from the organs and structures within your abdomen and chest (stomach, intestines, lungs, heart, etc.); and (2.) 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 that can 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 you also feel it in your skin and muscles, or the other way around. Up-regulation refers to increased nerve firing/signaling in the spinal cord and brain that are perceived as pain. This up-regulation may be due to chronic nerve stimulation or to changes in how the brain processes the nerve signals from the viscera or musculature. An important example of this process is the man or woman who becomes sexually aroused and feels their pelvic pain worsening.

3. Myofascial Dysfunction

Myofascial pain can be the primary source of pain, unrelated to organ pathology or a secondary source of pain due to a reflex response (visceral-muscular reflex). Often trigger points develop in the affected muscles. 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 may significantly reduce the pain. For others, the original source of injury as well as the trigger points must be treated. Nerves in the pelvis, such as the pudendal nerves, can also stimulate the pelvic muscles and cause myofascial pain.



4. Nerve Irritation

Several peripheral nerves surround the abdomen and the pelvis. These can be irritated or compressed individually in any one person, or there can be combinations of painful nerves that confuse both the patient and his/her doctors. The most commonly affected are the abdominal cutaneous nerves and the pudendal nerve although other nerves can be affected as well.

Abdominal cutaneous neuropathy is usually due to nerve injury. Ilioinguinal and iliohypogastric nerves can be injured during abdominal surgery or with exercise, heavy lifting, or an accident.

Pudendal Neuropathy:



There is a pudendal nerve on each side of the pelvis. It travels a twisting pathway after it forms from nerve fiber from sacral cord levels. Pressure may occur between two ligaments that French physicians call *the clamp* or *lobster claw*.

Pressure can be caused by coverings over the obturator internus muscle. The muscle is important in all hip rotations such as jogging, skating, yoga, etc. Only after a fall is the pain's onset immediate. Usually, the onset is slow and not recognized early (often referred to as repetitive microtrauma). Because the nerve can affect bladder, bowel, and/or sexual function it is called the "social nerve."

Bladder irritation and vulvar pain are common. Painful intercourse/orgasm/ejaculation can occur in many bizarre combinations. This is why patient and doctor may be confused in the diagnosis.

5. Action of the Brain.



Your brain influences your emotions and behavior. It also interacts with your spinal cord and affects how you perceive 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 to the brain. Certain regions of the brain are also “off-line” when you have chronic pain and may not be functioning effectively to inhibit pain signals. Sometimes the nervous system is overwhelmed by pain signals and there may be excessive sweating, nausea or loss of appetite, fatigue, and other problems.

It is important to remember that all of these levels of pain must be treated together (“multidisciplinary therapy”) for CPP therapy to be successful. Treatment of CPP can include psychological counseling, physical therapy, medications, nerve blocks, and surgery.

How Will My Doctor Diagnose CPP?

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



Here are a number of things you can do to help your doctor diagnose and treat you:



- Get copies of your medical records, including doctor visits, lab tests, ultrasounds or CATr or MRI scans, and surgical testing.
- If you have had surgeries, records of the surgical treatments (operative and pathology reports), including videotapes, are very helpful.
- Carefully fill out the doctor'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 doctor, the easier it will be for him/her to help you.
- Factors that may be very important in your care are:
 - ✓ How and when did your pain begin?
 - ✓ What actions or activities make it better or worse? (This may include sitting, driving, jogging, cycling, or working out at the gym)
 - ✓ Does stress increase the pain?
 - ✓ 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), excessive frequency of urination, constipation, diarrhea, or other problems with your bladder or bowels?
- ✓ Do you have pain with sexual activity?
- ✓ Has the pain caused emotional changes like anxiety or depression?

What has not worked?

- ✓ What medical or surgical treatments have you had?
- ✓ Have they helped?
- ✓ What have you done to relieve the pain?

What has worked?

- ✓ What medications have you used in the past?
- ✓ What medicines are you taking now?
- ✓ What do you think is causing your pain?
- ✓ What concerns you most about your pain?



Your doctor will do a very thorough physical exam. Remember that your pelvis is very important, not only for containing your female organs, but also because it provides support for your upper body and connects the upper body to the lower body. For these



reasons, not only will your reproductive organs, vagina or prostate, and rectum be examined, but also your posture, how you walk, your 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 doctor will also check closely for trigger points. A close examination of the vagina and also the labia (lips of the vagina) or penis and testes will be done. You will also have a rectal examination.

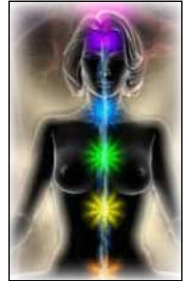
During these examinations, you may be asked at times to tense and relax specific muscles. When a nerve process is considered to be the cause, pinprick sensation testing would be done near the clitoris, at the vagina, and near the anus. Throughout all of this, your doctor will be looking for clues to damage or disease that might have started the pain, and clues to which nerves are contributing to the pain.

What Factors Will My Doctor Consider When Deciding How To Help Me?

Your doctor will consider a number of factors in deciding how best to treat your pain. Pain is in the nervous system, which includes the body and the mind. The pain is not all in your body, but it is not all in your head either! For a treatment to be effective, the doctor needs to treat the body and the mind.

CPP is not caused by a single problem but by a number of problems interacting together. This means that a single “treatment” may not work and a “multidisciplinary treatment” will be used. 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 doctor is trying to provide you with relief as quickly as possible. It took a long time for your pain to become so bad, and it may take weeks or months for it to completely go away. 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. Other medicines such as anticonvulsants, antidepressants, and local anesthetics are used for the abnormal nerve signaling that is present in most people with CPP (as discussed above). These are not pain pills/medications,” but are specifically designed to interrupt excessive pain signaling.

All medications can have side effects, especially narcotic analgesics. Your doctor 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 or hooked 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 doctor 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 doctor about how effective your pain medication is. Changing pain medication is not something your physician can easily do on the basis of a phone conversation.

If you and your doctor find it necessary to use strong narcotics 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 doctor finds you have been receiving prescriptions for narcotics from other physicians without permission from the doctor during your care, he/she may no longer provide care to you.

Some medications that alter pain processing, such as certain antidepressants or anticonvulsants, may also be prescribed. Pain that is worse during certain times of the menstrual cycle may also be treated with hormonal contraceptives.

What About My Muscle Aches And Pains?



Even if you're not aware of specific muscle aches per se, the muscular system is often involved in producing the CPP. Treating problems with your musculoskeletal system is an important part of your care. You may be referred to a physical therapist for an in depth evaluation. 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. The therapist 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 doctor to coordinate a program of exercises and pain medications by mouth and/or injection as needed.



Can Neuropathy Be Treated?

Several treatments are specific for neuropathy. Usually these are used along with some forms of physical therapy and almost always with medications to reduce nerve signaling (discussed earlier).

Self-care is a program to protect the nerve from further irritation/damage. It includes stopping activities that cause pain such as using the elliptical and doing abdominal crunches. Injections of anti-inflammatory steroid medications along with local anesthetic or local anesthetics alone can provide slow relief of nerve pain over three to four months. The bulk of nerve-pain patients respond to injections. Radio frequency ablation can sometimes be helpful.

When medications, injections, physical and cognitive behavioral/stress reduction therapy fails, surgery may be performed for pudendal neuropathy (i.e., to relieve pressure on the nerves). This group of patients is the most advanced in the nerve-pain group. Their pain recovery is much slower and in a small number, the nerves do not heal and more intensive treatments are needed.

Will I Be Treated For Emotional Pain and My Sensitized Central Nervous System ("Up-regulation")?



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 doctor must not only address the cause of the pain and pain relief, but also all the other problems it has caused.

Additionally, the way that pain signals are handled in the brain changes in everyone with chronic pain. This maladaptive change in the

way pain is processed by the brain can be normalized.

A number of different therapies will be used to help you overcome these common emotional consequences and changes in brain signaling. Learning to change the behaviors and thoughts that can contribute to your pain will relieve anxiety and depression, and increase your enjoyment of life and help to decrease pain. Some of the types of therapy that are used include cognitive behavioral therapy, relaxation therapy, and psychotherapy. Stress often makes pain worse. Stress can decrease the ability of the brain to inhibit up-regulated nerve firing and can contribute to myofascial dysfunction. Some forms of meditation such as mindfulness based meditation or yoga can be very helpful for many chronic pain problems, particularly those that increase with stress.

The pain you suffer also affects your family. They will 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 that will help them to support you in your recovery.

What About Surgical Treatments?



Depending on your individual circumstances, your doctor may decide to do surgery to determine the causes of your pain and possibly to treat them as well. If you have conditions such as endometriosis or scar tissue that are thought to be playing a role in your pain, these can often be treated under general anesthesia with the laparoscope and you can sometimes go home the same day. If nerve fibers such as the pudendal nerve are irritated or compressed in the pelvis, specific treatments would be needed to relieve the problem. This is similar to carpal tunnel syndrome. A small

number of patients with pudendal nerve compression causing their pelvic pain do not respond to other approaches and may need surgery to relieve compression (like carpal tunnel surgery in the buttocks).

So...What Can I Expect From Treatment For CPP?



First, you need to be realistic in your expectations and hopes for treatment. Some CPP can never be completely cured. Some individuals are so uncomfortable with the evaluation and testing process that they are never able to get a significant amount of pain relief.

Don't expect instant results. Be patient with your treatment and follow all your doctor's instructions. Treatment responses are often cumulative, meaning that a small result with each treatment builds on previous treatment response. Treatments may take up to three to six 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 doctor and therapist rather than just coming in when the pain is particularly bad. You may start with weekly or monthly visits. You and your doctor will decide whether these should be more or less frequent based on your progress. Be sure not to miss an appointment, as this can interfere with your treatment. If you miss an appointment and your pain becomes worse, it may take time to get it under control again. Often a multidisciplinary approach is needed, addressing any visceral pathology, myofascial dysfunction, nerve up-regulation, stress, and pain related anxiety or depression.

Remember that the treatment of CPP is a slow process, using many different kinds of therapy. It may not be possible to totally eliminate your pain. Successful treatment means decreasing your pain to a low level so that you are able to enjoy doing the things you want to do again. It means being able to be a wife or husband, mother or father, or be successful in your career with a minimum amount of discomfort.



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