

What should I do third?

Develop a diagnostic plan. This involves studying information about PN, making a tentative self-diagnosis, and then going to see the experts. Further details are on our website.

Is PNE treatable?

Yes. The sooner treatment begins the better. The main forms of treatment are:

- 1. Minimize sitting pressure** or anything that provokes pain.
- 2. Steroid injections** in places where the pudendal nerve may be entrapped, to attempt to shrink surrounding ligaments and tissues, which could reduce nerve pressure. Combined with less sitting, this has cured many cases.
- 3. Nerve decompression surgery.** *If steroids fail then surgery attempts to remove structural impediments to decompress and free up the nerve. Surgery is usually, but not always, successful.*

The International Pudendal Neuropathy Association

For further information please see:

www.tipna.org

There you will find a wonderfully friendly group of people with PN who can help you in many ways. We offer these forms of support:

- 1. Information** in the form of documents, images, and links.
- 2. Group discussion**, through forum messages.
- 3. Networking**, by contacting people you meet.

First study the *Frequently Asked Questions*. This gives a complete overview in easy to understand layman's language. After that, explore the website. If you conclude you may have PNE, see the *List of Doctors* and contact one. You may also want to read the group discussion messages or even participate in the discussion.

Good luck! We look forward to helping you.

Pudendal Nerve Entrapment

Do you have these symptoms?

- 1. Pain in the central sitting area, rectum, or external genitals.*
- 2. The problem is not going away on its own.*
- 3. The problem is not responding sufficiently to treatment of any kind.*
- 4. The pain gets worse when sitting and better when not sitting.*
- 5. The pain has no apparent cause, such as infection, injury, or a back problem.*

If you have some or all of these symptoms then you may have Pudendal Nerve Entrapment (PNE). At a minimum you must have 1, 2, and 3. Most people with PNE have all five.

What is PNE?

Pudendal Nerve Entrapment (PNE) is a nerve condition causing pain for no apparent reason in the area served by the pudendal nerve: the rectum, central sitting area, and scrotum and penis or vulva. Pain is usually worse when sitting and less when standing, lying down, or sitting on a toilet seat. No one pain pattern dominates. Pain can be in just one area, several, or all. It can be on one side, two sides, or the middle. Frequently there are also urinary, rectal, or sexual problems.

PNE is often misdiagnosed as *prostatodynia, nonbacterial prostatitis, idiopathic vulvodynia* (idiopathic means unknown cause), *idiopathic orchialgia, idiopathic proctalgia, idiopathic penile pain, coccydynia, Levator ani syndrome*, and for those with pain at the ischial tuberosities, as *ischial bursitis*.

PNE is a form of Pudendal Neuropathy (PN). Neuropathy means nerve damage or disease.

What Causes PNE?

The cause of PNE is similar to Carpal Tunnel Syndrome (CTS). The pudendal nerve has become entrapped due to your particular body's structure and lifestyle. In CTS too much repetitive wrist motion is the usual lifestyle culprit. In PNE prolonged sitting is the usual precipitator. This includes normal sitting, cycling, riding mowers, truck driving, etc. Injury, nearby surgery, constipation, or pelvic intensive activities such as weight lifting may also cause PNE to start.

In the case of too much sitting, excessive sitting pressure causes nerve or ligament irritation, which causes enlargement, which causes more pressure. A vicious cycle is born, causing the pain to increase gradually or suddenly. After this has occurred for awhile, the nerve begins to misbehave even when not sitting. Scar tissue may develop. The nerve is now "entrapped."

What should I do first?

The first thing to do is *stop making the problem worse*. Minimize your sitting time and when you do sit, sit

on a cushion with a cutout. This should be large enough to avoid pressure on the ischial tuberosities, the rectum, perineum and genitals. Don't try to be a hero and "tough it out." If you are engaging in a painful activity such as cycling, stop it altogether. *The more pressure the nerve receives and the longer it receives it, the more likely irreversible damage will occur, and therefore the lower the chance of successful treatment.*

What should I do next?

The second thing to do is *accept your condition for what it is*. Receipt of bad news initiates the well-known process of denial, anger, depression, bargaining, and finally, acceptance. This is the Cycle of Acceptance. *The reason you must come to accept your condition is that if you don't, you will be less rational*. This will cause two problems: you will probably make your condition worse, and you will not be able to self manage your case as well.