Patient Information



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This information was produced by the European Association of Urology (EAU), July 2021.

This chapter contains general information about chronic pelvic pain. If you have any specific questions about your individual medical situation you should consult your doctor or other professional healthcare provider. No website or leaflet can replace a personal conversation with your doctor.

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Chronic pelvic pain syndrome

About chronic pelvic pain syndrome

What is pain?

Pain alerts us to an injury, allowing us to protect our bodies. While everyone has their own way of describing pain, the widely accepted definition that it's an unpleasant sensation. Pain is something that we feel. It can range from mild discomfort to unbearable agony. It can be short-lived, known as acute pain, or it can be long-lasting, called chronic pain.

Pain is controlled by the nervous system – a complex network of nerves and cells that carry messages to and from your brain through your spinal cord.

The nerves in your spinal cord are divided into five main sections:

- Cervical (neck)
- Thoracic (middle back)
- Lumbar (lower back)
- Sacral (pelvis)
- Coccygeal (tailbone)

Sometimes the messages between the nerves in your spinal cord and your brain get confused and the brain cannot understand the signals properly. This can lead to chronic or persistent pain.

For people with chronic pelvic pain syndrome, the brain struggles to understand the signals from the sacral nerves, which supplies nerves to your pelvis, buttocks, genitals, thighs, calves, and feet.

What is chronic pelvic pain syndrome?

Chronic pelvic pain syndrome is a term used to describe several conditions where ongoing disabling pain is experienced around the pelvis with no identifiable cause. Sometimes shortened to CPPPS, chronic pelvic pain syndrome affects around 15% of women over 25, but it can also affect men.

Chronic pelvic pain conditions include:

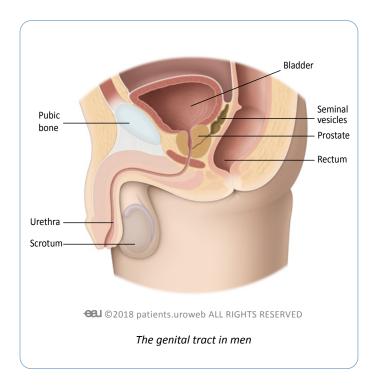
- Prostate pain syndrome
- Bladder pain syndrome
- Scrotal pain syndrome
- Urethral pain syndrome
- · Vaginal and vulvar pain syndrome

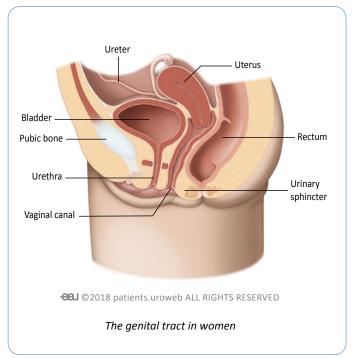
Pelvic region in men and women

The pain experienced can vary from person to person. You might have a mild ache or severe pain, it might feel dull or sharp, and it can be constant or come and go. But the condition doesn't just cause pain. You might also have:

- · difficulty peeing
- difficulty sleeping
- loss of interest in activities you previously enjoyed
- · feelings of anxiety or depression
- difficulty in maintaining or keeping an erection (men only)







The cause of chronic pelvic pain cannot always be identified. It may take several tests and checks over a few months before your doctor makes a diagnosis.

Living with chronic pelvic pain

It is not uncommon for people with chronic pelvic pain to feel anxious, isolated, withdrawn, and depressed. We know how the condition can affect not only your daily life, but those around you too.

Undergoing lots of tests and feeling like nobody understands what is causing your pain can be frustrating and upsetting. To help cope with these emotions, talk with your doctor about how you are feeling and how it affects your mental health.

Some people feel there is a social stigma attached to mental health problems, but the more we talk about mental health, the more it will become a normal part of society. You really shouldn't feel ashamed if your condition is affecting you in this way. There are treatments and talking therapies that can help. Some people find joining a support group, counselling, or behavioural therapy can help. In some cases, your doctor may recommend anxiety medication or anti-depressants.

About prostate pain syndrome

What is the prostate?

The prostate is a small gland that forms part of a man's reproductive system. It is about the size of a golf ball and surrounds the tube that empties urine from the bladder, called the urethra. The prostate makes a thick white fluid that mixes with sperm from your testicles to make semen.

What is prostate pain syndrome?

Although it is normal for the prostate to swell as a man gets older, this natural swelling does not usually cause any pain. But if you experience pain or discomfort around your prostate lasting more than 3 months, you may have prostate pain syndrome.

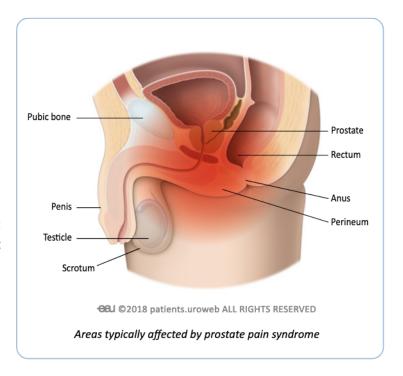


You may also hear prostate pain syndrome referred to as chronic prostatitis, chronic non-bacterial prostatitis, chronic prostate pain syndrome, or CPPS.

What causes prostate pain syndrome?

Prostate pain syndrome is the most common form of chronic pelvic pain in men. While we know some of the reasons people experience chronic pain, the exact cause of chronic prostate pain isn't always clear. What we do know is:

- It affects up to 15% of men
- It can occur in men of all ages, but it is most common in those between 30 and 50.
- It is not caused by an ongoing infection, so treatment with antibiotics will not help you



What are the common symptoms?

Men with prostate pain syndrome can experience ongoing pain, discomfort, and urinary problems, which can have a significant impact on their quality of life.

The most common symptoms include:

- · pain in and around your penis, particularly the tip, and your testicles
- pain around the anus or perineum
- pain in the lower abdomen, rectum, or lower back
- pain when urinating, a frequent or urgent need to pee, or "stop-start" peeing
- sexual problems, including erectile dysfunction, pain when ejaculating, or pelvic pain after having sex
- Blood in your semen (called haematospermia)

What tests and checks are available?

Your doctor will ask you about your symptoms and discuss your medical history, including any medication you take. He or she may examine your abdomen and back.

Pain and quality of life assessment

You may be asked to complete questionnaires designed to understand the severity of your pain and how it impacts your daily life. You may also be asked sensitive questions about any pain or difficulty you might experience before, during, or after sex, and how your condition affects your mental health.

Anxiety and depression can sometimes be difficult to talk about, but it's really important to be honest with your doctor about how you feel. You will not be judged by anyone, and your answers can help you get the support you need.

Perineum

The perineum is the area between your anus and scrotum.

Erectile dysfunction

Erectile dysfunction is the medical term for problems getting or keeping an erection.



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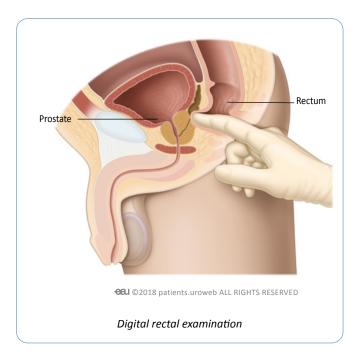
Urine test

You may be asked for a urine sample if your doctor thinks your symptoms might be caused by an infection. This may be sent to a laboratory for further testing, depending on the facilities available at your local clinic.

Prostate check

A prostate check, or digital rectal examination, is a quick and simple test to see if your prostate is enlarged or painful. It involves your doctor inserting a gloved and lubricated finger into your back passage (rectum) to feel your prostate.

You may be aware of some pressing and get a brief urge to pass urine. We realise this might seem embarrassing, but the examination is over very quickly. If your prostate is inflamed or swollen, the exam might be painful, but it will not cause lasting pain.



What treatments are available?

Acute prostatitis requires urgent antibacterial treatment. Treating prostate pain syndrome, however, can be difficult because it is not caused by an ongoing infection. The aim of treatment is to reduce your symptoms as much as possible to lessen the impact the condition has on your daily life.

Medication

Alpha-blockers

These medications help relax the muscles where your prostate joins your bladder and may ease your symptoms, such as painful urination.

Pentosane polysulphate sodium

Although this treatment is used to treat bladder pain, your doctor may prescribe you a course of pentosane polysulphate sodium capsules to see if this helps ease your prostate pain symptoms. You cannot take certain medications alongside pentosane polysulphate sodium, so it is important to make sure you read the information leaflet that comes with your medicine.

Over the counter

You doctor my recommend taking over the counter treatment, such as ibuprofen (an anti-inflammatory) or paracetamol (a pain killer), which may help you feel more comfortable.

If you regularly take anti-inflammatory or pain relief medication, talk to your doctor so that he or she can monitor you for possible side effects. These types of over-the-counter medications have a limit to how much pain they can control. You should not exceed the recommended daily dose as taking these medications beyond a certain dosage will not provide you with any additional benefit and may increase your risk of serious side effects.



Antibiotics

In some cases, if your doctor thinks your symptoms might be caused by an infection that isn't showing up on the recommended tests and checks for prostatitis, then you may be prescribed a single course of antibiotics to see if this relieves your symptoms.

Home remedies

You may find relief from the following home remedies:

- · Having warm baths or using a heat pad
- Limiting or avoiding alcohol, caffeine, and spicy or acidic foods
- Avoiding activities that can irritate your prostate, such as prolonged sitting or cycling.

Counselling

Cognitive behavioural therapy, or CBT, is a type of talking therapy. It is based on the idea that thoughts, feelings, what we do, and how our bodies feel, are connected. CBT aims to help you manage your pain by learning coping skills and changing the way you think and behave.

Your doctor may recommend CBT to help you cope with your condition. If your doctor hasn't suggested CBT but you think you would like to try it, mention it to your doctor and they can help you find a therapist.

Physiotherapy

Although physiotherapy is not a cure for chronic pain conditions, it may help you to reduce and manage your symptoms more effectively. Physiotherapy treatment involves correcting muscle imbalances by stretching, contracting, and strengthening the muscles. It can include light stretching and massage to release muscle tension, or targeted exercises, such as contracting and relaxing your pelvic floor muscle (found between your pubic bone and tailbone).

Physiotherapy is not always just about exercises. Your physiotherapist may also discuss lifestyle changes, education, and hands on treatment to help relieve your symptoms.

Nerve stimulation

Some men find their symptoms are lessened by nerve stimulation. As with all treatments, nerve stimulation may not be suitable for everyone, but your doctor will be able to discuss this with you.

The most common types of nerve stimulation for prostate pain syndrome include:

• Transcutaneous electrical nerve stimulation (TENS)

TENS therapy is a pain relief technique that uses a device to deliver mild electrical impulses through electrodes placed on painful areas of the body. The use of TENS treatment for prostate pain syndrome has been shown to be effective in clinical trials for around 50% of men.

Sacral nerve stimulation (SNS)

If your doctor recommends trying SNS, you will need to have a thin wire (called an electrode) inserted under your skin. The procedure is done under a local or general anaesthetic. A control unit, about the size of a mobile phone, is then used to change and control the frequency of electrical signals delivered to the electrode, which stimulates the sacral nerves.

• Posterior tibial nerve stimulation

Also called PTNS, this type of nerve stimulation involves having a tiny needle inserted into your foot which is used to send electrical pulses to the nerves around your pelvis.

Nerve stimulation can feel a little uncomfortable at first, but it is not painful. The treatment usually starts with a low level of intensity, and may be increased, but only up to a certain point where you still feel comfortable.



Alternative therapy

Acupuncture

Acupuncture is used to treat pain and involves inserting very thin needles through your skin at strategic points on your body. Your doctor may recommend a course of acupuncture treatment to help ease your symptoms.

Acupuncture has been shown to be an effective treatment for reducing prostate pain in clinical trials. So, even if you don't think it will work for you, it's worth giving it a try!

Phytotherapy

Phytotherapy is a natural treatment for chronic prostate pain that combines two specific formulations of the supplement's <u>quercetin</u> and pollen extract. These supplements have antioxidant and anti-inflammatory effects to help reduce inflammation and pain.

About bladder pain syndrome

What is the bladder?

Your bladder is the organ that stores urine produced by your kidneys. It is a bag-shaped muscle that, when full, contracts allowing urine to pass through the urethra.

What is bladder pain syndrome and what causes it?

People with bladder pain syndrome experience long-term pain around the pelvis and problems urinating. It's also called interstitial cystitis or painful bladder syndrome.

Bladder pain syndrome does not have any obvious cause, like an infection. It is thought that the condition may be caused by damage to the bladder from previous infections, an allergic reaction, or an immune response, where your body mistakenly attacks the bladder.

The condition is more common in women than men. It is usually diagnosed between 30 to 40 years of age, but it can affect all age groups, including children and young people.

Bladder Urethra Rectum October 10 to 10

What are the common symptoms?

Bladder pain syndrome is not caused by an infection, but it can feel like a bladder infection. Symptoms can be mild to severe. Some people describe it as a mild ache that comes and goes, while for others, the pain is constant and severe enough to affect their sleep, work, and everyday activities. Some women may feel pain during or after having sex.

The most common symptoms of bladder pain syndrome include:

- pain when your bladder is full that may be temporarily relieved after urinating
- severe pain in the area below your bellybutton
- pain in the lower back
- a sudden and strong urge to pee
- needing to pee more often than normal
- waking up several times during the night to go to the toilet

Quercetin

Quercetin is a phytonutrient, or plant chemical, found in many fruits and vegetables.



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You may also find the pain is worse after having certain foods or drinks, during times of physical or emotional stress, or with certain activities like sitting too long. Women may find the severity of their symptoms can change during their menstrual cycle (period).

If you are experiencing any of these symptoms, talk to your doctor. The sooner you get a diagnosis, the sooner your doctor can help you get the treatment you need.

What tests and checks are available?

Pain and quality of life assessment

Your doctor will need to get a complete picture of the bladder pain, pressure, or discomfort you feel when your bladder is full and empty. You may be asked to complete questionnaires designed to understand the severity of your pain and how it impacts your daily life. You may also be asked sensitive questions about any pain or difficulty you might experience before, during, or after sex, and how your condition affects your mental health.

Anxiety and depression can sometimes be difficult to talk about, but it's really important to be honest with your doctor about how you feel. You will not be judged by anyone, and your answers can help you get the support you need.

Physical examination

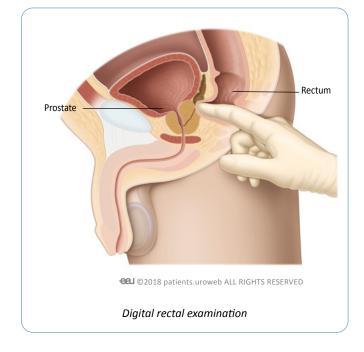
Your doctor will ask you to describe your symptoms and perform a physical examination to feel for any tenderness around your pelvis and abdomen. We know it can be very embarrassing, but your doctor may recommend a pelvic exam that involves examining your genitals (vagina and cervix in women and penis and scrotum in men) to check for further tenderness.

Prostate check (men only)

A prostate check, or digital rectal examination, is a quick and simple test to see if your prostate is enlarged or painful. It involves your doctor inserting a gloved and lubricated finger into your back passage (rectum) to feel your prostate.

We realise this might seem embarrassing, but the examination is over very quickly. You may be aware of

some pressing and get a brief urge to pass urine. The exam may feel uncomfortable. If your prostate is inflamed or swollen, you may find it a little painful, but it will not cause lasting pain.



Urine test

You may be asked for a urine sample if your doctor thinks your symptoms might be caused by an infection. This may be sent to a laboratory for further testing, depending on the facilities available at your local clinic. The results can help your doctor understand if there is a cause for your symptoms.



Cystoscopy

Your doctor may arrange for you to have a cystoscopy, which is a procedure to look inside your bladder using a thin camera called a cystoscope. We realise you may be feeling anxious about having a cystoscopy, but the examination will help your doctor rule out known causes of bladder pain.

A cystoscopy can be uncomfortable or painful for people with bladder pain. You may be offered a local anaesthetic to numb the urethra while the camera is passed through it into your bladder, a general anaesthetic where you'll be asleep during the procedure, or a spinal anaesthetic which will numbs the lower half of your body.

What treatments are available?

Because it is not known exactly what causes bladder pain syndrome, there is no single treatment that works for everyone, but there are various treatments you can try. We understand how frustrating this can be, but we encourage you to keep trying different options until you find a treatment or a combination of treatments that relieve your symptoms.

Diet and lifestyle

Some people find their bladder pain is worse after having certain foods or drinks, during times of physical or emotional stress, or with certain activities. If you know what triggers your pain, then you may be able to make adjustments that reduce your symptoms.

You may find the following helpful:

- cutting down on, or eliminating alcohol, caffeinated, or citrus drinks
- limiting high-acid foods that may contribute to bladder irritation and inflammation
- taking regular breaks from sitting down and moving around
- if you regularly cycle, limit the duration of this activity
- try activities that help you relax and reduce your stress levels

Medications

Pentosane polysulphate sodium

Pentosane polysulphate sodium is a weak blood thinner that is approved as a treatment for bladder pain. It is not known exactly how it works, but it is thought to help repair the protective layer of mucus that lines your bladder, reducing inflammation and pain. You cannot take certain medications alongside pentosane polysulphate sodium, so it is important to make sure you read the information leaflet that comes with your medicine.

Over the counter

If your symptoms are mild, your doctor may recommend taking anti-inflammatory drugs or painkillers, such as ibuprofen or paracetamol, to help relieve your pain. You may also be prescribed a course of antihistamines to help control the urge to urinate.

If you regularly take anti-inflammatory or pain relief medication, talk to your doctor so that he or she can monitor you for possible side effects. These types of over-the-counter medications have a limit to how much pain they can control. You should not exceed the recommended daily dose as taking these medications beyond a certain dosage will not provide you with any additional benefit and may increase your risk of serious side effects.



Anti-depressants

If your symptoms are severe, treatment that aims to relax the nerves may be beneficial. Medication such as amitriptyline has been shown to relax the bladder, so it may be an effective treatment for you. And if your symptoms are affecting your mood, you may find anti-depressants help improve how you are feeling and control some of the pain.

We realise you may feel there is a social stigma attached to mental health and taking anti-depressants, but you should not feel ashamed of the negative impact a chronic condition like bladder pain syndrome can have on your mental wellbeing.

Physiotherapy

Although physiotherapy is not a cure for chronic pain conditions, it may help you to reduce and manage your symptoms more effectively. Physiotherapy treatment involves correcting muscle imbalances by stretching, contracting, and strengthening the muscles. It can include light stretching and massage to release muscle tension, or targeted exercises, such as contracting and relaxing your pelvic floor muscle (found between your pubic bone and tailbone). Physiotherapy is not always just about exercises. Your physiotherapist may also discuss lifestyle changes, education, and hands on treatment to help relieve your symptoms.

Nerve stimulation

Some people find their symptoms are lessened by nerve stimulation. As with all treatments, nerve stimulation may not be suitable for everyone, but your doctor will be able to discuss this with you.

The most common types of nerve stimulation for bladder pain syndrome include:

• Transcutaneous electrical nerve stimulation (TENS)

TENS therapy is a pain relief technique that uses a device to deliver mild electrical impulses through electrodes placed on painful areas of the body. The use of TENS treatment for prostate pain syndrome has been shown to be effective in clinical trials for around 50% of men.

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If your doctor recommends trying SNS, you will need to have a thin wire (called an electrode) inserted under your skin. The procedure is done under a local or general anaesthetic. A control unit, about the size of a mobile phone, is then used to change and control the frequency of electrical signals delivered to the electrode, which stimulates the sacral nerves.

Posterior tibial nerve stimulation

Also called PTNS, this type of nerve stimulation involves having a tiny needle inserted into your foot which is used to send electrical pulses to the nerves around your pelvis.

Nerve stimulation can feel a little uncomfortable at first, but it is not painful. The treatment usually starts with a low level of intensity, and may be increased, but only up to a certain point where you still feel comfortable.

Counselling

Cognitive behavioural therapy, or CBT, is a type of talking therapy. It is based on the idea that thoughts, feelings, what we do, and how our bodies feel are connected. CBT aims to help you manage your pain by learning coping skills and changing the way you think and behave.

Your doctor may recommend CBT to help you cope with your condition. If your doctor hasn't suggested CBT but you think you would like to try it, mention it to your doctor and they can help you find a therapist.



Intravesical therapy (bladder wash)

Intravesical therapy is the medical term for a bladder instillation, sometimes also called a bladder wash. It is a treatment where a liquid drug is administered into the bladder to coat the lining with a protective layer which can help reduce your symptoms.

The procedure involves having a catheter inserted into your bladder via your urethra. Once your bladder has been filled with the liquid drug you will be advised not to pee for a specified amount of time to allow the drug to work.

Botulinum toxin

Botulinum toxin works by paralysing nerve endings. You may have heard this called Botox[®]. While most of us think of botulinum toxin as a cosmetic procedure to reduce the signs of ageing, botulinum toxin injections have several medical purposes including muscle and nerve-related health problems. For example, botulinum toxin is used as a treatment for overactive bladder syndrome in people who have not had success with other treatment options.

If your symptoms are severe, your doctor may suggest a course of botulinum toxin injections. This type of treatment has been shown to provide symptom relief for around one-third of patients, but it isn't suitable for everyone. Your doctor will be able to advise you if botulinum toxin is a treatment option for you.

About scrotal pain syndrome

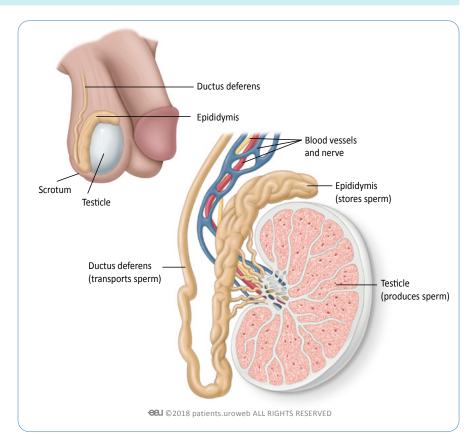
What is the scrotum?

Your scrotum is the bag of skin that holds your testicles. Each testicle produces hormones, the main one being testosterone. Your testicles contain the cells responsible for producing sperm. Your scrotum also helps to protect your testicles, major blood vessels and nerves, as well as the tubes that store and transport sperm, called the epididymis and ductus deferens.

What is scrotal pain syndrome?

Scrotal pain syndrome, also called chronic orchialgia or testicular pain syndrome, is pain in one testicle or both testicles that lasts for at least 3 months. The pain might be constant, or it may come and go. It might feel like a dull ache, or it could be severe.

We know scrotal pain can be very worrying for you and can affect your quality of life. We hope the information you find here will help you to understand more about the potential cause of your pain and treatments that might help you.



Overactive bladder syndrome
Overactive bladder, also called OAB, causes a frequent and sudden urge to urinate that may be difficult to control.



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What causes scrotal pain syndrome?

Scrotal pain can be caused by several treatable conditions, but in up to 50% of men, the cause of the pain is unknown, which is referred to as scrotal pain syndrome. It can be frustrating for you, especially if you have seen several doctors and still feel as though you have no answers. In this instance, a referral to a urologist may be the best way forward. The pain can also happen following trauma or following a vasectomy or hernia repair. Up to 20% of men who have had a vasectomy and 10% who have had a hernia repair report experiencing scrotal pain within the months following their surgery.

What are the common symptoms?

The most common symptoms of scrotal pain syndrome include:

- mild or severe pain that lasts for at least 3 months
- groin pain when you move around or perform strenuous activity
- a feeling of heaviness or tender areas around your scrotum
- severe pain in your scrotum that happens without warning
- urinating more than usual
- blood in your urine or semen

What tests and checks are available?

Pain and quality of life assessment

You may be asked to complete questionnaires designed to understand the severity of your pain and how it impacts your daily life. You may also be asked sensitive questions about any pain or difficulty you might experience before, during, or after sex, and how your condition affects your mental health.

Physical examination

Your doctor will ask you to describe your symptoms and perform a physical examination of your genitals. We know it can be very embarrassing, but your doctor will need to touch and press your testicles to check for swelling, tenderness, abnormal skin changes, and feel for any lumps. He or she may also check for any tenderness around your pelvis, lower abdomen, and around your groin.

Ultrasound

An ultrasound uses sound waves to send images to a computer. It allows your doctor to see inside your testicles and the surrounding tissues in your scrotum and help rule out known causes of scrotal your pain.

What treatments are available?

Medications

There is no specific medication developed to treat scrotal pain syndrome, but your doctor may still recommend medication that might help manage your symptoms. These may include:

- anti-inflammatory and pain relief medication like ibuprofen or paracetamol
- anti-depressants, such as amitriptyline, which is commonly used to treat chronic pain
- antibiotics if your doctor thinks you might have an infection that hasn't been detected on tests

Home remedies

Like so many other chronic conditions, scrotal pain syndrome is poorly understood. If you have unexplained scrotal pain, then the following home remedies might be helpful:

- take anti-inflammatory and pain relief medication like ibuprofen, or paracetamol
- use a heat pad or take a warm bath
- avoid lifting heavy objects or strenuous exercise
- wear tighter underwear to limit the movement of your scrotum



If you regularly take anti-inflammatory or pain relief medication, talk to your doctor so that he or she can monitor you for possible side effects. These types of over-the-counter medications have a limit to how much pain they can control. You should not exceed the recommended daily dose as taking these medications beyond a certain dosage will not provide you with any additional benefit and may increase your risk of serious side effects.

Physiotherapy

Although physiotherapy is not a cure for chronic pain conditions, it may help you to reduce and manage your symptoms more effectively. Physiotherapy treatment involves correcting muscle imbalances by stretching, contracting, and strengthening the muscles. It can include light stretching and massage to release muscle tension, or targeted exercises, such as contracting and relaxing your pelvic floor muscle (found between your pubic bone and tailbone).

Physiotherapy is not always just about exercises. Your physiotherapist may also discuss lifestyle changes, education, and hands on treatment to help relieve your symptoms.

Nerve block and cord stripping

If you do not experience any relief from home remedies, your doctor may discuss having a nerve block. A nerve block involves having an anaesthetic injected into the spermatic cord. It is not necessarily a treatment but can help determine where your pain is coming from. The outcome will help your doctor decide if cord stripping would be a successful treatment for you. In some cases, your doctor might recommend having a repeat nerve block to see if it relieves your pain.

Cord stripping, or <u>microsurgical</u> denervation of the spermatic cord, is a microsurgical technique performed under anaesthetic, so you will not feel anything during the surgery. It involves removing the nerves in the spermatic cord and has been shown to permanently relieve testicle pain in around 75% of men.

Vasovasostomy

If your doctor believes your scrotal pain is caused by a vasectomy, you may want to consider having a reverse vasectomy, called a vasovasostomy. When you had your vasectomy, the tubes that transport sperm, called the vas deferens, were cut. During a reverse vasectomy, your surgeon will reconnect the two ends of the vas deferens. Clinical studies have shown that around 80% of men who have a reverse vasectomy have an improvement in their scrotal pain. However, it can take a few months to experience this relief.

About urethral pain syndrome

What is urethral pain syndrome and what causes it?

The urethra is the thin tube that transports urine from the bladder and out of your body. In men, the urethra also carries semen from the testicles during ejaculation.

Urethral pain syndrome is the medical term for a group of symptoms that can occur making it difficult or painful to pee but without any known cause. The condition is most common in women, but adults of any age can develop the syndrome.



Microsurgical

Microsurgery is an intricate surgery performed using miniaturised instruments and a microscope.



What are the common symptoms?

The symptoms of urethral pain syndrome are very similar to urinary tract infections (UTIs) and a condition called <u>urethritis</u>. But, while UTIs and urethritis are caused by bacterial and viral infections, the symptoms in urethral pain syndrome occur without having an infection or any obvious medical cause.

Common symptoms of urethral pain syndrome include:

- needing to pee more often than usual or the bladder not feeling empty after urinating
- pain during urination or in the abdomen
- a sudden urge to urinate
- pain in the lower back or genitals
- pain during sex
- blood in your urine
- swollen testicles, pain while ejaculating, or blood in your semen (men only)

What tests and checks are available?

Pain and quality of life assessment

You may be asked to complete questionnaires designed to understand the severity of your pain and how it impacts your daily life. You may also be asked sensitive questions about any pain or difficulty you might experience before, during, or after sex, and how your condition affects your mental health.

Physical examination

Your doctor will ask you to describe your symptoms and may need to perform a physical examination of your genitals. We know it can be very embarrassing, but your doctor will be checking for swelling, tenderness, abnormal skin changes, and feeling for any lumps. He or she may also check for any tenderness around your pelvis and lower abdomen.

Urine test

Your doctor will want to rule out an infection as a cause of your symptoms, so you will be asked to provide a urine sample. This may be sent to a laboratory for further testing, depending on the facilities available at your local clinic.

Sexually transmitted disease (STD) check

Your doctor may recommend having a urethral swab to check for sexually transmitted diseases (STDs), such as chlamydia or gonorrhoea, which can cause painful inflammation in and around your pelvic area. Even if you haven't had a sexual partner recently, you should still consider having the test as not all STDs causes symptoms.

For women, a urethral swab involves having a cotton bud gently inserted into your urethra, which will be turned to collect a sample of cells. A sample may also be collected from the entrance to the womb, called the cervix.

For men, a urethral swab involves having a cotton bud gently inserted about 2 centimetres (three-quarters of an inch) into the urethra and then turned.

In both instances, the test doesn't take very long, but it can feel uncomfortable. The samples will be sent to a laboratory to check for any bacteria.

Cystoscopy

Your doctor may arrange for you to have a cystoscopy to look for any other potential causes of your symptoms. A cystoscopy is a procedure to look inside the bladder using a thin camera called a cystoscope.

Urethritis

Urethritis is an inflammation of the urethra. It is not the same as a urinary tract infection, which affects the urinary tract.



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Ultrasound

An ultrasound uses sound waves to send images to a computer. It allows your doctor to see inside your pelvic region and get a detailed look at the surrounding tissues to help rule out known causes of pain in and around the urethra.

What treatments are available?

Home remedies and lifestyle changes

Because urethral pain syndrome can have several causes, your doctor may recommend trying home remedies and lifestyle changes that reduce possible irritation to the urethra to see if this helps to improve your symptoms.

These may include:

- avoiding the use of scented products around your genitals such as perfumes, soaps, or bubble bath
- avoiding the use of certain contraceptives such as diaphragms and spermicidal jellies and opting for condoms instead
- avoiding the use of perfumed or scented sanitary products and tampons (women only)
- · reducing your intake of caffeinated drinks and drinking water instead
- limiting the amount of spicy food you eat
- avoiding activities that put excessive pressure on your urethra (such as cycling, horse riding, or riding a motorcycle)
- · urinating shortly after sex

Medications

There is no specific medication developed to treat urethral pain syndrome, but your doctor may still recommend medication that might help manage your symptoms. These may include:

- anti-inflammatory and pain relief medication like ibuprofen or paracetamol
- anti-depressants, such as amitriptyline, which is commonly used to treat chronic pain
- alpha-blockers to help relax the muscles around your pelvis, which might ease your symptoms, such as painful urination
- antibiotics if your doctor thinks you might have an infection that hasn't been detected on tests

If you regularly take anti-inflammatory or pain relief medication, talk to your doctor so that he or she can monitor you for possible side effects. These types of over-the-counter medications have a limit to how much pain they can control. You should not exceed the recommended daily dose as taking these medications beyond a certain dosage will not provide you with any additional benefit and may increase your risk of serious side effects.

Nerve stimulation

Some people find their symptoms are lessened by nerve stimulation. As with all treatments, nerve stimulation may not be suitable for everyone, but your doctor will be able to discuss this with you.

The most common types of nerve stimulation that might be offered to you as a treatment for urethral pain syndrome include:

• Transcutaneous electrical nerve stimulation (TENS)

TENS therapy is a pain relief technique that uses a device to deliver mild electrical impulses through electrodes placed on painful areas of the body. The use of TENS treatment for prostate pain syndrome has been shown to be effective in clinical trials for around 50% of men.



• Sacral nerve stimulation (SNS)

If your doctor recommends trying SNS, you will need to have a thin wire (called an electrode) inserted under your skin. The procedure is done under a local or general anaesthetic. A control unit, about the size of a mobile phone, is then used to change and control the frequency of electrical signals delivered to the electrode, which stimulates the sacral nerves.

• Posterior tibial nerve stimulation

Also called PTNS, this type of nerve stimulation involves having a tiny needle inserted into your foot which is used to send electrical pulses to the nerves around your pelvis.

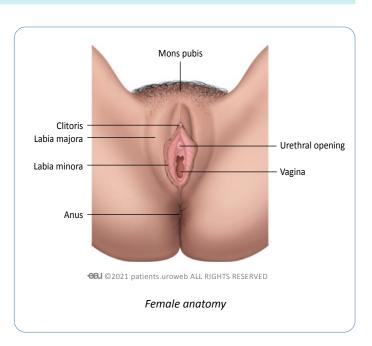
Nerve stimulation can feel a little uncomfortable at first, but it is not painful. The treatment usually starts with a low level of intensity, and may be increased, but only up to a certain point where you still feel comfortable.

About vaginal and vulvar pain syndrome

What is the difference between the vulva and the vagina?

The vulva is the medical term for your genitals, including the mons pubis, labia majora and minora, clitoris, opening of the urethra, and the vagina. The vagina connects to your uterus, or womb, and is the canal that babies pass through during childbirth, as well as your menstrual flow.

Many women prefer to use the term vagina, despite knowing the difference in terminology. When talking about your condition with your doctor, whatever word you prefer to use is okay - you need to feel as comfortable as possible when talking about embarrassing topics.



What is vaginal and vulvar pain syndrome?

Vaginal and vulvar pain syndrome is also known as vulvodynia or chronic vaginal pain.

Vaginal and vulvar pain syndrome is persistent, unexplained pain in a woman's genital area. The pain can occur in different areas of the vulva at different times, called generalised pain, or occur at the entrance of the vagina, called focal pain.

It can happen to women of all ages and be very distressing. The condition can affect your relationships, reduce your sex drive, and cause you to experience low mood and depression.

It's important to know that vaginal and vulvar pain is not infectious. It is not related to cancer, and you will not pass it on to your partner.



What causes vaginal and vulvar pain syndrome?

The condition can be caused by an infection, trapped nerves, or nerve damage caused by:

- previous surgery
- childbirth
- · repeat episodes of severe vaginal thrush
- hormonal changes

In some cases, the condition may be triggered by a sensitivity to the products you are using, skin conditions, or immune system disorders.

What are the common symptoms?

Vaginal and vulvar pain is often described as either a burning sensation that comes on only after touch or pressure, such as during sex or when inserting a tampon. It can also be more widespread with no specific trigger.

What tests and checks are available?

Pain and quality of life assessment

You may be asked to complete questionnaires designed to understand the severity of your pain and how it impacts your daily life. You may also be asked sensitive questions about any pain or difficulty you might experience before, during, or after sex, and how your condition affects your mental health.

Physical examination

Your doctor will ask you to describe your symptoms and will need to ask you about your sexual history. So, you may be asked if you have ever had vaginal infections, vaginal dryness and if it hurts when you have sex.

Please be aware that your doctor may ask you if you have ever been a victim of sexual abuse. This is because vaginal and vulvar pain can be caused by trauma to the vulva. We realise this can be a very upsetting topic to talk about, especially if it is something that you haven't discussed before. Try to be as open and honest as you feel comfortable.

Your doctor will need to perform a physical examination of your vulva, including your vagina. We know it can be very embarrassing, but your doctor will be checking for swelling or tenderness. He or she may also check for any tenderness around your pelvis and lower abdomen.

Swab test

Your doctor may recommend having a urethral swab to check for:

- Sexually transmitted diseases (STDs), such as chlamydia or gonorrhoea, can have no symptoms but cause painful
 inflammation in and around your pelvic area.
- Bacterial vaginosis, a common infection caused by an imbalance in naturally occurring bacteria.
- Vaginal thrush is a common infection caused by an increase of Candida albicans, a yeast that lives naturally in the bowel and in small numbers in the vagina.

A urethral swab involves having a cotton bud gently inserted into your urethra, which will be turned to collect a sample of cells. A sample may also be collected from the entrance to the womb, called the cervix.

Immune system disorders

Your immune system is your body's natural defence system. It protects your body from harmful substances, bacteria and cell changes that could make you ill. It is made up of various organs, cells, and proteins. If you have an immune system disorder, your immune system mistakenly attacks your body.



The test doesn't take very long, but it can feel uncomfortable or painful if your condition is triggered by touch. The samples will be sent to a laboratory for testing.

What treatments are available?

Home remedies and lifestyle changes

Your doctor may recommend trying home remedies and lifestyle changes to help reduce as much irritation to the vulva as possible, such as:

- wearing cotton underwear and loose-fitting skirts or trousers
- · avoiding the use of scented products around your genitals such as perfumes, soaps, or bubble bath
- · avoiding the use of perfumed or scented sanitary products and tampons
- using petroleum jelly before swimming to help protect the vulva from chlorine
- using a doughnut-shaped cushion when sitting for prolonged periods

Although having sex can be painful, try not to avoid it (or touching your vulva) completely, as this may make you more sensitive.

Medication

Over the counter

There are some over the counter treatments, such as lubricants, aqueous cream, which may help to soothe the vulva, and aesthetic gels that can help make having sex more comfortable. It is best to talk to your doctor first to see if he/she recommends them for you.

Anti-depressants

Anti-depressants are often used to treat conditions where the nerves are hypersensitive. The medication aims to relax the nerves. Your doctor may recommend a course of anti-depressants to see if this helps ease your pain.

Counselling

Cognitive behavioural therapy, or CBT, is a type of talking therapy. It is based on the idea that thoughts, feelings, what we do, and how our bodies feel are connected. CBT aims to help you manage your pain by learning coping skills and changing the way you think and behave.

If your condition affects your intimate relationship, then your doctor may recommend a specific type of counselling that aims to help you cope with the fear and anxiety that can happen when you have pain affecting your vagina and vulva.

Physiotherapy

Your pain may be triggered by spasms of the muscles around your pelvic floor. These muscles are found between your pubic bone and tailbone. You doctor may recommend support for a physiotherapist to teach you a series of exercises designed to help relax the muscles around your vagina.

Physiotherapy isn't always just about targeted exercises. Your physiotherapist may also discuss lifestyle changes, education, and treatment such as vaginal cones or the use of a TENS machine to help relieve your symptoms.



TENS

Transcutaneous electrical nerve stimulation (TENS) is a method of pain relief involving the use of a mild electrical current.



My notes and questions



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