



Fact Sheet

Pelvic Pain

About

Chronic pelvic and genital pain can be caused by a number of conditions, some of which overlap, and can affect men, women and children. Common causes of chronic pelvic and genital pain in women include endometriosis, vulvodynia, and interstitial cystitis. Research has found that there are often a number of pain-related conditions associated with one another, or are “comorbid.” For example, in about 20% of women with endometriosis, studies have shown that it co-occurs with other chronic pain conditions, such as irritable bowel

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syndrome, interstitial cystitis/painful bladder syndrome, vulvodynia, temporomandibular disorders, migraine, fibromyalgia, and/or with autoimmune disorders such as systemic lupus erythematosus, rheumatoid arthritis, chronic fatigue

syndrome, and Sjogren’s syndrome.¹ Chronic pelvic pain can be an issue for men as well as women. For example, though interstitial cystitis (IC) has traditionally been considered a “women’s” disease, men also get IC. For both sexes, many of the challenges are similar, even with regard to intimacy-related pain.²

Interstitial Cystitis

Interstitial cystitis is a condition that results in recurring discomfort or pain in the bladder and the surrounding pelvic region.³ The symptoms vary from case to case and even in the same individual. People may experience mild discomfort, pressure, tenderness, or intense pain in the bladder and pelvic area. Symptoms may include an urgent need to urinate (urgency), a frequent need to urinate (frequency), or a combination of these symptoms. Pain may change in intensity as the bladder fills with urine or as it empties. Women’s symptoms often get worse during menstruation. They may sometimes experience pain with vaginal intercourse.⁴

IC symptoms in men are similar to those experienced by women: pelvic pain, urinary urgency, and urinary frequency. But these symptoms overlap with conditions that are more common in men, especially chronic prostatitis/chronic pelvic pain syndrome (CP/CPPS), and also urinary tract and prostate infection and benign prostatic hyperplasia, or prostate enlargement.⁵

New research supports that IC is much more prevalent than originally thought. The total and the proportion of men with IC is much higher than originally estimated. An estimated 3 to 8 million women in the United States may have IC. That is about 3 to 6% of all women in the U.S. Additionally, an estimated 1 to 4 million men have IC as well, however, this number is likely lower than the true rate because IC in men may often be mistaken for another disorder, such as chronic prostatitis/chronic pelvic pain syndrome.⁶

Endometriosis

Endometriosis is a condition where tissue similar to the lining of the uterus (the endometrial stroma and glands, which should only be located inside the uterus) is found elsewhere in the body. Endometriosis lesions can be found anywhere in the pelvic cavity: on the ovaries, the fallopian tubes, and on the pelvic sidewall. Other common sites include the uterosacral ligaments, the cul-de-sac, the Pouch of Douglas, and in the rectal-vaginal septum. In addition, it can be found in caesarian-section scars, laparoscopy or laparotomy scars, and on the bladder, bowel, intestines, colon, appendix, and rectum. In rare cases, endometriosis has been found inside the vagina, inside the bladder, on the skin, even in the lung, spine, and brain.

The most common symptom of endometriosis is pelvic pain. The pain often correlates to the menstrual cycle, but a woman with endometriosis may also experience pain that doesn't correlate to her cycle. For many women, the pain of endometriosis is so severe and debilitating that it impacts their lives in significant ways. Endometriosis can also cause scar tissue and adhesions to develop that can distort a woman's internal anatomy. In advanced stages, internal organs may fuse together, causing a condition known as a "frozen pelvis."⁷

Symptoms of endometriosis include:⁸

- Pain before and during periods
- Painful urination during periods
- Pain with sexual intercourse
- Painful bowel movements during periods
- Infertility
- Other gastrointestinal upsets such as diarrhea, constipation, nausea
- Fatigue

At least 5.5 million women in North America have endometriosis. About 30-40% of women with endometriosis are infertile, making it one of the top three causes for female infertility. The two most common symptoms of endometriosis are pain and infertility.⁹ Migraine is more frequent in women with endometriosis than in controls, although its presence and characteristics are not related to the severity of endometriosis.¹⁰

Approximately 47% of women with endometriosis see at least five health care professionals before receiving a diagnosis and/or referral.¹¹

Vulvodynia

Vulvodynia is a chronic condition characterized by pain and burning in the vulva in the absence of infection or other known disease. The most commonly reported symptoms are burning, stinging, and/or rawness. Some women describe the pain as “acid being poured on their skin” or as “constant knife-like pain.” The condition varies in persistence and location. Pain may be constant or intermittent, localized or diffuse. Vulvar vestibulitis, one type of vulvodynia, refers to pain experienced primarily when pressure is applied to the vulvar vestibule, the area surrounding the vaginal opening; this pain typically occurs with sexual intercourse, tampon insertion, a gynecological exam or simply sitting.¹²

According to the National Vulvodynia Association, approximately 6 million women currently suffer from vulvodynia.¹²

Vulvodynia is not caused by either an active infection or a sexually transmitted disease. The causes are unknown because of the lack of research on the disorder. Current studies are investigating potential causes and trying to determine risk factors for developing vulvodynia. Researchers speculate that one or more of the following may cause, or contribute to, vulvodynia:¹²

- An injury to, or irritation of, the nerves that supply sensation to the vulva
- An abnormal response of different cells in the vulva to environmental factors (such as infection or trauma)
- Genetic factors associated with susceptibility to chronic vestibular inflammation
- A localized hypersensitivity to candida (yeast)
- Spasm or weakness of the pelvic floor musculature

Vulvodynia affects women of all age groups, beginning as early as adolescence. According to an NIH-funded Harvard study, approximately 9-16% of U.S. women suffer from vulvodynia at some point during their lives.¹³

The incidence of symptom onset of vulvodynia is highest between the ages of 18 and 25, and lowest after age 35. Once considered a condition that affects primarily Caucasian women, several recent studies have shown that African American and Hispanic women are equally likely to develop vulvodynia.¹⁴

According to a Harvard study, 60% of women consult at least three doctors in seeking a diagnosis. Astoundingly, 40% of those who seek professional help remain undiagnosed after three medical consultations.¹⁴ Living with vulvodynia imposes serious limitations on a woman's ability to engage in normal daily activities. In many cases, the pain is so severe and unremitting that it forces women to resign from career positions, abstain completely from sexual relations and limit many physical activities, often destroying a woman's self-image. In addition, because genital disorders are not openly discussed, women with vulvodynia experience isolation and hopelessness.¹⁴ According to an NIH-funded study at Robert Wood Johnson Medical School:¹³

- 75% of women with vulvodynia feel “out of control” of their bodies
- 60% cannot have sexual intercourse because of the pain
- 60% report that it compromises their ability to enjoy life

Facts

An estimated 4 to 25% of women have chronic pelvic pain (CPP), but only about a third of them seek medical care.¹⁵

CPP is also one of the most common reasons American women see a physician, accounting for 10% of gynecologic office visits, up to 40% of laparoscopies, and 20% of hysterectomies in the U.S. Total treatment costs may run as high as \$2.8 billion annually.¹⁵

An estimated 25% of women with CPP may spend 2-3 days in bed each month. More than 50% of women with chronic pelvic pain must cut down on their daily activities one or more days a month.¹⁵

Despite the number of possible causes, up to 61% of women with CPP receive no diagnosis.¹⁵

After endometriosis, the second most common cause of CPP is pelvic inflammatory disease (PID). PID is one of the most common gynecologic conditions, usually related to a sexually transmitted disease. As many as 30% of women with PID develop CPP.¹⁵

Additional Resources

American College of Obstetricians and Gynecologists

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Phone: (202) 638-5577
www.acog.org

American Urological Association Foundation

1000 Corporate Boulevard
Linthicum, MD 21090
Phone: (866) RING-AUA (746-4282)
Phone: (410) 689-3700
E-mail: patienteducation@auafoundation.org
www.UrologyHealth.org

American Urogynecologic Society

2025 M Street NW., Suite 800
Washington, DC 20036
Phone: (202) 367-1167
Fax: (202) 367-2167
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www.augso.org

Centers for Disease Control and Prevention

1600 Clifton Road
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Endometriosis Association

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Interstitial Cystitis Association of America

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International Pelvic Pain Society

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www.pelvicpain.org

National Institute of Child Health and Human Development

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Phone: (800) 370-2943
TTY: (888) 320-6942
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Mail: P.O. Box 3006, Rockville, MD 20847
E-mail:
NICHDInformationResourceCenter@mail.nih.gov
www.nichd.nih.gov/health

National Kidney and Urologic Diseases Information Clearinghouse

3 Information Way
Bethesda, MD 20892-3580
Phone: (800) 891-5390
TTY: (866) 569-1162
Fax: (703) 738-4929
E-mail: nkudic@info.niddk.nih.gov
www.urologic.niddk.nih.gov

National Women's Health Resource Center

157 Broad Street
Suite 106
Red Bank, NJ 07701
Phone: (877) 986-9472
Fax: (732) 530-3347
www.healthywomen.org

National Vulvodynia Association

PO Box 4491
Silver Spring, MD 20914-4491
Phone: (301) 299-0775
Fax: (301) 299-3999
www.nva.org/index.html

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Resources verified July 2011.

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