



## What is pelvic pain?

Pelvic pain is pain felt below the belly button and above the legs and is sometimes, but not always, associated with menstrual periods. Pelvic pain can also be caused or exacerbated by a range of gynaecological, gastrointestinal, urological, and neuromuscular conditions.

If a woman experiences continuous or recurrent pelvic pain over a six-month period, it may be defined as persistent pelvic pain. Endometriosis is the most common condition that contributes to persistent pelvic pain. Persistent pelvic pain is a complex, multifactorial and poorly understood condition which cannot be fully encompassed by or understood through any one diagnosis alone.

### How does pelvic pain affect women?

Pelvic pain in women is underdiagnosed, and often debilitating.<sup>5</sup> Women have described their experiences with pelvic pain as 'relentless' and 'overwhelming'.<sup>2</sup> Affecting around 15% of women globally, persistent pelvic pain causes significant disruptions to everyday life, including to social relationships, sexual function, work performance, and mental health.<sup>6,7</sup> Persistent pelvic pain is the most common cause of work absenteeism for women of childbearing age and creates an estimated economic burden of \$6.5 billion per annum in Australia.<sup>8,5</sup> The stigmatisation of pelvic pain further isolates women, causing shame and embarrassment.<sup>2</sup>

Pelvic pain affects women through their life course, often beginning with painful periods in adolescence. Almost three quarters of young women report regular period pain. Recent Australian research found that 3 out of 10 young women reported having to skip class at school or university due to menstrual symptoms in the past three months. This not only has implications for their education and workforce participation, but also for social activities and wellbeing. Young women's experiences with pelvic pain are particularly salient, as conditions such as endometriosis often develop in the teenage years and remain undiagnosed for years. Pelvic pain continues to impact women throughout their lives.

Persistent pelvic pain has far-reaching effects on the functioning of a woman's body, often causing a constellation of additional symptoms such as poor sleep, memory difficulties, and mood disorders.<sup>4</sup> Women with persistent pelvic pain require long-term medical care, and undergo gynaecological surgery and hysterectomy at much higher rates than women without persistent pelvic pain.<sup>12</sup>

#### What is the relationship between persistent pelvic pain and mental health?

The relationship between mental health and experiences of persistent pelvic pain is complex. Women with persistent pelvic pain have significantly higher rates of psychological disorders, such as

Sometimes referred to as chronic pelvic pain, persistent pelvic pain is the preferred term.



depression and anxiety, than women who do not suffer this pain. Among women with persistent pelvic pain, between 26-52% will experience depression and between 39-73% will experience anxiety. The comorbidity of psychological distress and persistent pain leads to higher health care costs, lower quality of life, and greater limitations in daily life. Additionally, women who feel as though their pain symptoms have been dismissed or disbelieved are less likely to disclose their psychological symptoms. 12

The disbelief and minimisation of women's experiences of pelvic pain, in addition to the challenges presented by living with persistent pain, predispose women to developing conditions such as depression or anxiety. However, new research has found biological connections between psychological disorders and pelvic pain, in addition to these social and environmental factors. These research findings suggest that the genetic causes for endometriosis and depression may be shared, and that the inflammatory response caused by depression may trigger inflammation which causes pelvic pain. These discoveries highlight the importance of continued research into women's pelvic pain, to fully understand its causes and develop effective treatment options.

## Why is pelvic pain underdiagnosed and mismanaged?

Early detection and treatment of pelvic pain and its cause can prevent the transition from acute to persistent pain and minimise the likelihood of women experiencing life-long persistent pain.<sup>4</sup> However, despite the significant impact of pelvic pain on quality of life and the importance of early detection and treatment, women often struggle to be believed and diagnosed.<sup>2</sup>

Women's reproductive health conditions have historically been under-prioritised by the medical profession, which has resulted in women's pain being undiagnosed, misdiagnosed, dismissed and stigmatised. The underdiagnosis and mismanagement of women's pelvic pain stems from gendered attitudes that trivialise and stigmatise women's experiences. Rooted in the history of 'hysteria', symptoms which cannot be medically explained – due to medicine's limited understanding of women's pelvic pain – are dismissed as non-serious or imaginary. The interval of the medical strategies of the medical

At the same time, women's pelvic pain is normalised as an expected part of womanhood and menstruation, and it is assumed that all women's experiences with pelvic pain are the same. When pelvic pain is normalised, women who seek help for their pain can face stigma and be labelled 'difficult' or 'needy'. As a result, many women who experience persistent pelvic pain are not believed or taken seriously by their family, friends, or healthcare providers. These myths can also mean that women choose to put up with the pain and delay seeking medical support.

In addition, women have been routinely excluded from clinical trials due to concerns over pregnancy risks and the management of female hormonal cycles. This means that, although women are more likely to experience a persistent pain condition, pain research has primarily been conducted on male animals and humans. As a result, many of the conditions which cause persistent pelvic pain in women do not have direct treatment options.

The lack of prioritisation of women's reproductive healthcare is also reflected in medical education. Many healthcare providers lack guidance and education on pelvic pain and are not equipped to effectively manage pelvic pain and the health conditions which cause it.<sup>19</sup>



### How does lack of understanding of pelvic pain impact women's access to healthcare?

Lack of understanding of – and dismissive attitudes towards – women's pain has serious impacts on women's health and access to healthcare including:

- Poor quality of care and distrust in the medical system leading to delayed diagnosis of health conditions which cause pelvic pain.<sup>20,21</sup>
- Women being less likely to receive pain relief in a healthcare setting or waiting longer to receive it.<sup>22</sup>
- Women who experience persistent pain conditions being more likely to have their symptoms inappropriately attributed to depression or anxiety, compared to men experiencing pelvic pain.<sup>2</sup>

### What does good quality pelvic pain management look like?

Multidisciplinary care with patient education and involvement have been shown to have the best outcomes for treating pelvic pain.<sup>23</sup> Women with pelvic pain have described good quality pelvic pain management and care as including:

- receiving compassionate care from a supportive and understanding health care team;
- having their pain believed and taken seriously;
- receiving an explanation for their pain;
- being reassured that they are not alone in their experience of pelvic pain; and
- being reassured that treatment options are available.<sup>2</sup>

This requires health care practitioners to listen to women and give them adequate time to share their experiences, communicate clearly, and actively involve women in their treatment plan.<sup>20</sup>

### Spotlight author

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# WHV thanks the following expert reviewers for their input:

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#### **Overview**

Pelvic pain: a collection of helpful resources Jean Hailes, 2020

Pelvic pain 2019 Pelvic Pain Foundation of Australia, 2019

Chronic pelvic pain in women Best Practice Journal, 2015

Chronic pelvic pain: a complex condition requiring informed care Croakey, 2019

The cost of illness and economic burden of endometriosis and chronic pelvic pain in Australia: a national online survey PLoS One 2019

Gender bias and the ongoing need to acknowledge women's pain Practical Pain Management, 2018

## Women's experiences of pelvic pain

Storylines: Her Voice Matters Women's Health Goulburn North East and Women's Health Loddon Mallee, 2018

What women say about their dysmenorrhea: a qualitative thematic analysis BMC Women's Health, 2018

Why some women ignore sexual discomfort and settle for bad sex ABC Online, 2020

<u>Vaginal mesh has caused health problems in many women, even as some surgeons vouch for its safety and efficacy</u> *Washington Post*, 2019

Why some doctors don't take women's pain seriously ABC Online, 2019

## Pelvic pain and mental health

Anxiety and depression in patients with endometriosis: impact and management challenges International Journal of Women's Health, 2017

Impact of endometriosis on quality of life and mental health: pelvic pain makes the difference Journal of Psychosomatic Obstetrics and Gynecology, 2015

The psychological profile of women presenting to a multidisciplinary clinic for chronic pelvic pain: high levels of psychological dysfunction and implications for practice *Journal of Pain Research*, 2016

<u>Psychology of chronic pelvic pain: prevalence, neurobiological vulnerabilities, and treatment</u> *Clinical Obstetrics and Gynecology,* 2019

The relationship between endometriosis-related pelvic pain and symptom frequency, and subjective wellbeing BMC Health and Quality of Life Outcomes, 2019



## Pelvic pain in adolescents

<u>Dysmenorrhea</u>, endometriosis and chronic pelvic pain in adolescents Journal of Clinical Research in Pediatric Endocrinology, 2019

The prevalence and academic impact of dysmenorrhea in 21,573 young women: a systematic review and meta-analysis Journal of Women's Health, 2019

Menstrual health literacy and management strategies in young women in Australia: a national online survey of young women aged 13-25. *Journal of Pediatric and Adolescent Gynecology*, 2020

3 out of 10 girls skip class because of painful periods: and most won't talk to their teacher about it *The Conversation*, 2020

#### **Treatment**

Making chronic pelvic pain a little less painful Contemporary Ob/Gyn, 2019

An international survey of commonly used interventions for management of pelvic pain Journal of Women's Health Physical Therapy, 2019

A systematic review of drug treatment of vulvodynia: evidence of a strong placebo effect BJOG, 2018

A review of physiotherapy pain management strategies in the management of patients with chronic pelvic pain Pain and Rehabilitation, 2015

Outcomes following multidisciplinary management of women with residual pelvic pain and dyspareunia following synthetic vaginal mesh and/or mesh sling removal Journal of Women's Health Physical Therapy, 2019

<u>Self-management strategies to consider to combat endometriosis symptoms during the COVID-19 pandemic Human Reproduction Open, 2020</u>

### **Practice resources and guidelines**

Pelvic pain in women: what's the diagnosis? Guidelines In Practice, 2017

Management of persistent pelvic pain in girls and women Australian Family Physician, 2015

<u>Localised provoked vestibulodynia (vulvodynia): assessment and management</u> *Australian Family Physician,* 2015

Raising Awareness Tool for Endometriosis (RATE) Royal Australian and New Zealand College of Obstetrics and Gynaecology, 2020



#### References

- Bush D, Evans S, Vancaillie T (2011) <u>The \$6 billion woman and the \$600 million girl</u> Pelvic Pain Steering Committee. Norwood, S.A.
- 2. (2015) Chronic pelvic pain in women Best Practice Journal, 70(Sep):6-16.
- 3. Bloski T, Pierson R (2008) Endometriosis and chronic pelvic pain: unravelling the mystery behind this complex condition Nursing For Womens Health, 12(5):382–395.
- 4. Coopes A (2019) Chronic pelvic pain: a complex condition requiring informed care Croakey, (Oct 29):1.
- 5. Mainwaring J (2019) Pain and the pelvis Jean Hailes Magazine, 2019(1):8-10.
- 6. Facchin F, Barbara G, Saita E, et al. (2015) <u>Impact of endometriosis on quality of life and mental health:</u> pelvic pain makes the difference Journal of Psychosomatic Obstetrics and Gynecology, 36(4):135-141.
- 7. Curran N (2015) Commentary on the influence of gender on the management of chronic pelvic pain BJOG, 122(6):766-768.
- 8. Armour M, Lawson K, Wood A, et al. (2019) The cost of illness and economic burden of endometriosis and chronic pelvic pain in Australia: a national online survey PLoS One 14(10): e0223316.
- 9. Armour M, Hyman MS, Al-Dabbas M, et al. (2020) Menstrual health literacy and management strategies in young women in Australia: a national online survey of young women aged 13-25 Journal of Pediatric and Adolescent Gynecology. 34(2):135-143. Accessed: Nov 2020.
- 10. Jean Hailes (2016) Endometriosis: fact sheet Jean Hailes for Women's Health. Clayton, Vic.
- 11. Schliep K (2018) A lifecourse approach to studying pelvic pain in women BJOG, 125(12):1540.
- 12. Till S, As-Sanie S, Schrepf A (2019) <u>Psychology of chronic pelvic pain: prevalence, neurobiological vulnerabilities, and treatment</u> *Clinical Obstetrics and Gynecology*, 62(1):22-36.
- 13. Lagana A, La Rosa V, Rapisarda A, et al. (2017) <u>Anxiety and depression in patients with endometriosis:</u> impact and management challenges *International Journal of Women's Health* 2017(9):323-330.
- 14. Adewuyi E, Mehta D, Sapkota Y (2020) <u>Genetic analysis of endometriosis and depression identifies shared loci and implicates causal links with gastric mucosa abnormality</u>, *Human Genetics*, 140(3):529-552.
- 15. Graziottin A, Skaper S, Fusco M (2013) <u>Inflammation and chronic pelvic pain: a biological trigger for depression in women? *Journal of Depression and Anxiety*, 3(1):1000142.</u>
- 16. Miller A (2018) Gender bias and the ongoing need to acknowledge women's pain Practical Pain Management, 18(5):1.
- 17. Dusenbury M (2018) Pain in women: hysteria or misjudgment? Practical Pain Management, (Aug 14):1.
- 18. Shaheed H (2017) Stop telling women their suffering is normal: pain should be treated The Guardian, (Oct 24):1.
- 19. Evans S (2015) Management of persistent pelvic pain in girls and women Australian Family Physician, 44(7):454-459.



- 20. Wygant J, McGuire L, Bush N, et al. (2019) What makes a chronic pelvic pain patient satisfied? Journal of Psychosomatic Obstetrics and Gynaecology, 40(3):239-242.
- 21. Alvaro A (2018) Persistent pelvic pain: women suffer in silence amid ignorance and stigma ABC News, (May 25):1.
- 22. Billok J (2018) Pain bias: the health inequality rarely discussed BBC Online. The Health Gap, (May 22):1.
- 23. Estes K (2018) Chronic pelvic pain resolved best with interdisciplinary approach Practical Pain Management (website).

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