

Pelvic pain

A silent epidemic

Susan was 16 when she tried to tell her doctor about the pain she experienced around the time of her period, but he just waved her off, saying: “Oh, that’s normal women’s stuff, you’ll get used to it.”

But if the doctor had let her, Susan would have told him that she missed at least two days of school a month, and this was showing in her slipping grades.

She would also have described the unrelenting pain as being like broken glass cutting into her and that she often wept when she opened her bowels or passed urine.

She might also have said that sometimes she got so down from not knowing what was wrong with her, that she didn't feel she could go on.

Susan reflected on this consultation ten years later, when the fertility specialist informed her that she may never have children, as a result of her undiagnosed and untreated pelvic scarring. She thought how different things might have been if only that doctor hadn't dismissed her pain.

What is pelvic pain?

Pelvic pain (PP) affects up to 1 in 10 women and is abnormal pain below the belly button. Pain can be acute, occurring for a limited time and often related to something like a period or chronic pain that lasts for longer than 3 months.

Causes

PP has multiple causes, not all of them well understood. Conditions associated with PP include endometriosis, adenomyosis (occurs when endometrial tissue grows into the muscle wall of the uterus), pelvic inflammatory disease, irritable bowel syndrome, painful bladder syndrome, pudendal nerve damage, pelvic floor pain, vulvodynia, pelvic adhesions, ovarian cyst pathology, pain following trauma, and cancers.

The last taboo

PP may be one of the last taboos within our society. The lack of awareness and medical attention on PP may be a direct result of our reluctance to talk about so-called *women's business*.

The silent epidemic

PP is often referred to as the silent epidemic because of the difficulty women experience, particularly young women, in getting an early and accurate diagnosis.

It's a common experience for women to visit doctors on multiple occasions and still not receive an accurate diagnosis. In some conditions such as endometriosis, it may take over eight years from the time a woman experiences symptoms to an accurate diagnosis. This unacceptable delay can lead to a worsening of symptoms which may decrease a woman's chances of pregnancy. In addition, it is known that women with endometriosis lose up to 11 hours per week due to excessive pain, resulting in loss of significant time at school or work.

Severe period pain is unacceptable

One of the main reasons women have so much difficulty getting an accurate diagnosis and treatment is due to a belief held by the general community and health professionals, that severe period pain is normal. Susan's doctor was echoing a commonly shared view that it's a woman's lot in life to experience pain. But according to Jean Hailes expert and gynaecologist Dr Elizabeth Farrell, this is not correct. She says:

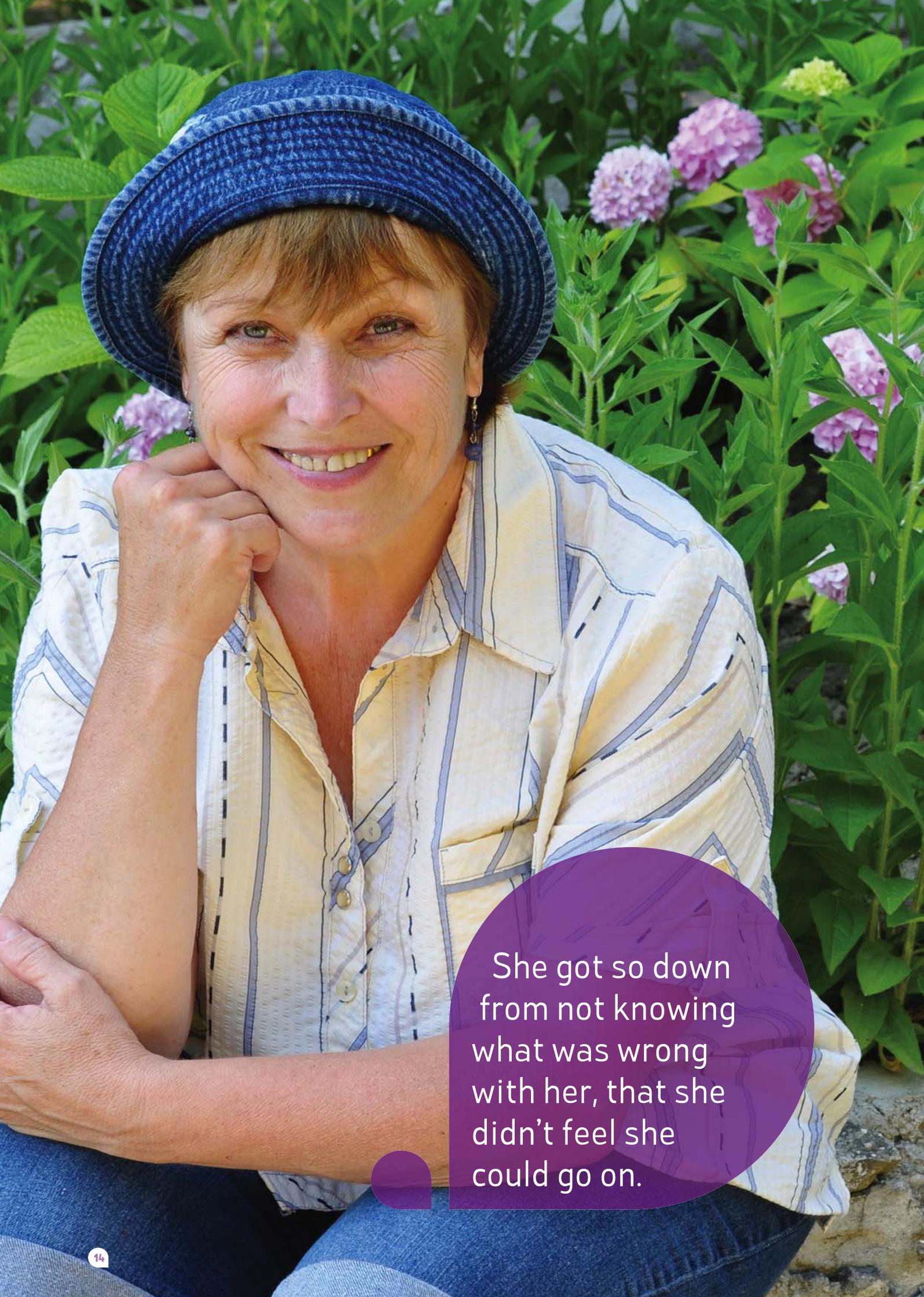
"As a society we need to challenge the idea that it is all right for women to suffer with their periods. If any woman is missing school or work or is unable to participate in her life generally, then this is not normal and not acceptable."

Another reason why women have difficulty getting a diagnosis and treatment is that PP varies a great deal between women, but the most prominent symptom is pain.

How to get an accurate diagnosis

Health professionals need to take action when a woman says she has severe period pain and women need to persist in their search for answers.





She got so down from not knowing what was wrong with her, that she didn't feel she could go on.

Common diseases associated with pelvic pain

Endometriosis

A chronic and progressive condition where cells normally found in the uterus (endometrial cells), are found outside the uterus. These cells are thought to backflow out of the fallopian tubes into the pelvic area and can stick to organs in the pelvis such as the ovaries, bladder or to the peritoneum (internal lining) especially down behind the uterus. Although these cells are outside of the uterus they may continue to respond to hormonal stimulation, particularly the hormone oestrogen, and grow and bleed.

Early diagnosis and treatment may prevent the progression of the disease to cause scarring and adhesions. Common treatments include the oral contraceptive pill and pain medications, which may reduce the symptoms, but a laparoscopy (looking inside the pelvis) and removal of the endometrial tissue is required to diagnose and treat endometriosis.

Irritable bowel syndrome

Symptoms include abdominal pain, bloating and alternating constipation and diarrhoea. The cause is unknown, but factors such as emotional stress, infection and some foods can aggravate the condition. Treatment options include dietary modifications, stress management and medications that reduce bowel spasm.

Vulval conditions

A range of vulval conditions can cause PP, such as vulvodynia and lichen planus.

Bladder pain syndrome

A condition that results in recurring discomfort or pain in the bladder and the surrounding pelvic region, symptoms vary between individuals 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 and/or frequent need to urinate. 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 during vaginal intercourse.

Asherman's syndrome (AS)

A condition resulting from scarring within the uterus, most likely caused by a set of circumstances including recent pregnancy, curettage and inflammation (possibly due to infection) and a genetic tendency. The majority of AS patients have no symptoms at all. Some women may have reduced bleeding as blood may be trapped in the uterine cavity due to scarring. Often women become aware they have this condition when they fail to become pregnant or if they have increasing period pain.

Pudendal nerve damage

The pudendal nerve runs from the lower back, along the top of the pelvic floor muscles, through to the base of the pelvis and out to the perineum. Pudendal nerve pain may be like an irritation or compression of the pudendal nerve by fibrosis of the surrounding tissues or ligaments. The main symptom is pain which may be like a burning or electric shock in the vagina, anus and pelvis, which leads to difficulty sitting for prolonged periods of time. Pudendal nerve pain may be related to childbirth, vaginal surgery, cycling, trauma and straining, or it may have no obvious cause. There may be bladder, bowel or sexual problems.

Pelvic floor spasm

Overactive pelvic floor muscles, which causes PP and dyspareunia.

Cancers

A range of cancers can cause PP.

Who can help?

Women who experience PP may have a range of health professionals working with them: GPs, gynaecologists, pelvic physiotherapists, pain specialists, dietitians experienced in food intolerance, psychologists, vulval dermatologists, psychiatrists and gastroenterologists experienced in the management of bowel symptoms.

What can be done?

Currently there are no known prevention methods. However, a leading expert in PP, Professor Thierry Vancaillie, says that if women receive effective care when they first visit a doctor they may avoid longer term problems such as dependence on pain medications, psychological deterioration and infertility. Effective treatment has the potential to improve the quality of women's lives greatly. Appropriate investigations must be undertaken to attempt to find the cause of PP, and even if the cause is not found, appropriate treatment of symptoms is required.

Where to find more information

Jean Hailes for Women's Health
endometriosis.org.au

Endometriosis Care Centre of Australia
ecca.com.au

The Endometriosis Association (QLD)
qendo.org.au

Endometriosis New Zealand (ENZ)
nzendo.co.nz

Women's Health and Research Institute of Australia
whria.com.au