

AWHF

Surveying the Silence

Exploring the Impact of Taboos
in Women's Health

AlbertaWomensHealthFoundation.org

In partnership with

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AWHF - WHO WE ARE

Land Acknowledgment

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The Alberta Women's Health Foundation respectfully acknowledges that we are on the traditional territories of Alberta of the many First Nations, Métis, and Inuit whose footsteps have marked these lands for centuries, including Treaty 4, Treaty 6, Treaty 7, Treaty 8, and Treaty 10 land. Our main office is located on traditional lands referred to as Treaty 6 Territory, and all the people here and in the surrounding area are beneficiaries of this peace and friendship treaty. Treaty 6 encompasses the traditional territories of numerous western Canada First Nations such as the Cree, Saulteaux, Blackfoot, Metis, Dene and Nakota Sioux. We acknowledge all the many First Nations, Metis and Inuit people who have called these areas home since time immemorial.

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Foreword: A Letter from Our CEO

Last year, we launched a report entitled, *“Finding the Fractures: The Pandemic, Women’s Health Disparities, and the Path to Equity.”*

We learned much about the unique struggles and experiences of women in Alberta throughout the pandemic. COVID-19 impacted the lives of so many people in so many ways—within our homes, our families, our workplaces, and our relationships. Many respondents reported decreased mental and physical health, relationship difficulties, and reduced access to healthcare as a result of the pandemic.

While many of these learnings were difficult to read, we as the Alberta Women’s Health Foundation (AWHF) did our best to outline the many ways we could collectively work toward improving our community’s health, support each other, and navigate unique challenges in health and healthcare.

As is our mission, we continue to walk the path toward equity. We continue to press for more knowledge in women’s health.

While we continue to feel the impacts of the pandemic, our work in the community has revealed that these feelings of isolation, hopelessness in different facets of life, and difficulty accessing healthcare are, sadly, not exclusive to the pandemic.

Challenges like these are faced by women in our province on a daily basis.

For this next report, we looked past the pandemic. Instead, we focused on the quiet places. The topics our culture leads many of us to avoid, or the questions we do not know to ask. The conditions about which little is known, and according to our respondents, even less is done, such as menopause, endometriosis, painful periods and PMDD, PCOS, pelvic floor issues, and more. The pain and discomfort associated with these conditions often hangs in the air unmentioned—or when voiced, can result in tension, confusion, and even dismissal by healthcare providers.

And so, silence.

The silence around certain health conditions and topics in women’s health has played a role in the many disparities in care and research that still exist today.

Foreword

With the launch of this report, sharing data from the over 2,200 respondents who shared their voices, we aim to raise more awareness and understanding of these conditions and support important research.

Thankfully, others have joined our cause.

We would like to gratefully acknowledge Organon Canada, the AWHF's first strategic partner and our first-ever sponsor of a thought leadership report such as this. Through Organon's generous contributions and global leadership in healthcare, we are better able to amplify the voices of so many Albertans and carry out our all-important work of shining light in the darkness. We will take crucial steps together toward a better, healthier future for all, united by the shared belief that women are foundational to a healthier world.

With partners like Organon, our research partner Women and Children's Health Research Institute (WCHRI), and those who will soon add their voices to ours, we are confident we can begin to dispel the silence and open the door for more productive conversations to advance women's health.

Thank you for your attention, thank you for your support, and thank you for sharing your voice.

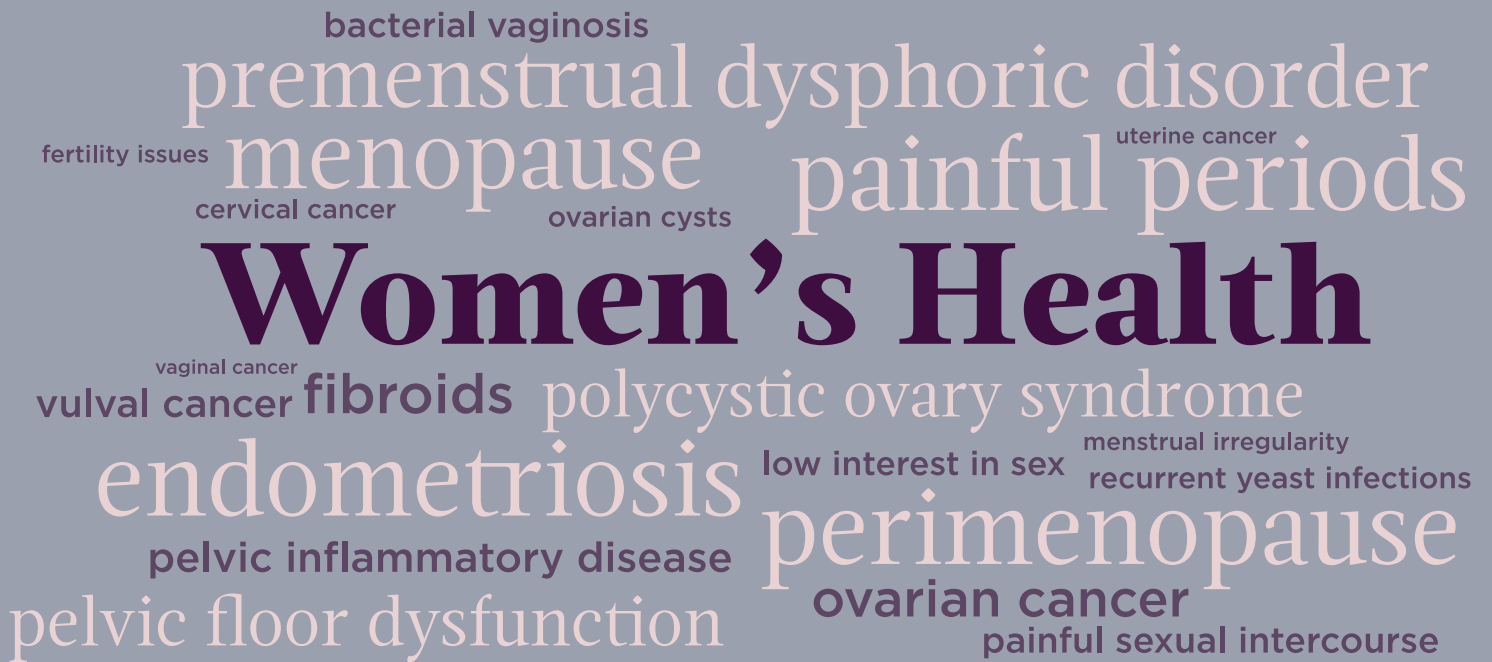
Sincerely,



Sharlene Rutherford

President and Chief Executive Officer
Alberta Women's Health Foundation
Royal Alexandra Hospital Foundation

Women's Health Conditions



Introduction

While around 50% of the population are assigned female at birth as women, it's still taboo to talk about many of the health issues related to their specific anatomy. Women's health goes far beyond pelvic anatomy and associated conditions, but reproductive and gynecological organs and associated hormones considerably impact women, transgender men and non-binary individuals.

At the Alberta Women's Health Foundation (AWHF), we are on a mission to support the advancement of care and research in women's health. Tackling taboos is part of this.

Taboos are social customs restricting discussion on specific topics. They create a culture of silence that limits access to knowledge and care and can harm individuals' overall mental health and well-being. Taboos perpetuate discrimination and negative stereotypes, isolate women, and contribute to inequities.

For example, research in Canada shows that 4 out of 5 young persons who menstruate have tried to hide that they are on their period, and 58% have felt ashamed or embarrassed about it. Canada ranks in the bottom half of countries surveyed regarding society's support of talking openly about periods.

Women's health has been deprioritized for decades, with limited research, funding, misdiagnoses, minimized symptoms and adverse health impacts from treatment. We are determined to ensure taboos stop contributing to these inequities.

We surveyed over 2,220 people in Alberta, most self-identified women, to understand their top health issues, concerns, and experiences with seeking health for conditions associated with their pelvic anatomy. In this report, we explore the impact of these taboos and seek to bring attention to medical conditions affecting women's lives in our province.

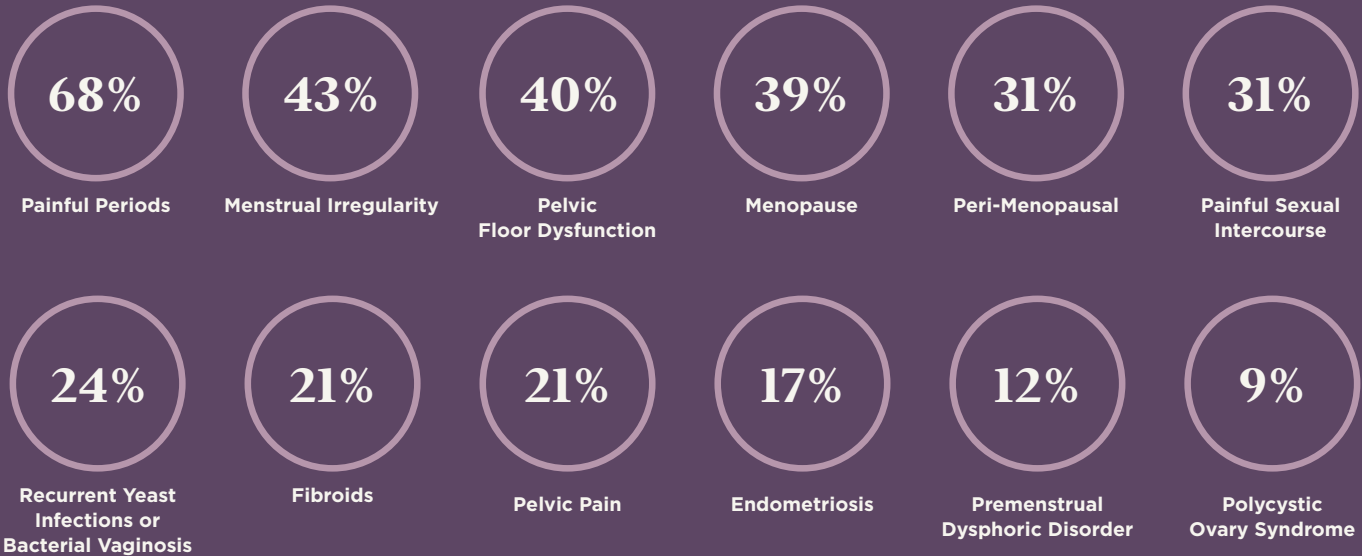
Women (n.)

All people who identify as women.

We acknowledge that sex relates to a person’s physical and biological features at birth. Gender is a multidimensional concept influenced by factors including cultural and behavioural norms and self-identity. As this concept is affected by ongoing societal change, gender is constantly evolving. We use the term “women” to refer to all people who identify as women. Still, we recognize that many of the health issues in this report apply to women, trans men and non-binary individuals assigned female at birth.

Taboo Health Issues for Women in Alberta

The purpose of the survey was to understand the unique challenges of women's health in Alberta and, in particular, women's gynecological health. Women experienced an average of five pelvic health issues each, specifically the following:



Almost two-thirds of women surveyed found it difficult to talk to primary healthcare providers about their concerns. Only 24% of women feel their physician is very knowledgeable about gynecological and reproductive health. Delays in treatment were commonly reported, and where a diagnosis is more complicated or specialized, such as endometriosis, a delay was reported by as many as 85% of sufferers. One in five respondents feels that their gender is a barrier to receiving care.

Treatment effectiveness is another area of concern; more women report treatment for perimenopause is ineffective (39%) than highly effective (35%). The highest satisfaction in treatment for a diagnosed condition was for endometriosis, at just 44%, once a diagnosis was achieved.

Women also highlighted that even they had limited knowledge about their gynecological and reproductive health, with only one quarter feeling very knowledgeable.

The Consequences of Making Women's Health Issues "Taboo"

The impacts of keeping the narrative of women's health issues taboo are multifaceted, but all can have harmful effects on women's health and the health of broader society.

"It adds worry and stress because you don't know what and when to expect and if strange new symptoms are indicative of something serious."

- Survey respondent suffering from perimenopause

Lack of awareness of what is normal

The culture of silence means women are not aware of what is "normal." They prevent women from discovering they are not the "only ones" going through something or seeking help. Taboo and shame create discomfort in discussing concerns around stigmatized topics with healthcare providers and may also result from bad advice from less reputable sources.

Inaction linked to worse outcomes

Lack of preventative health care also leads to worse outcomes. For example, cervical cancer is the third most common reproductive cancer in Canadian women and can be preventable with a vaccine. The five-year survival rate is 93% with early detection but is as low as 15% with later-stage diagnosis. Thus, screening is critical, and avoiding screening due to the taboo of women's pelvic health causes many to miss screening, increasing their risk for worse health outcomes.

Normalized conditions

As a society, we have normalized many women's health issues, like painful menstruation. Even the portrayal of women in the media reinforces the notion that women should not let their periods prevent them from doing anything. Many women have had their symptoms dismissed by loved ones and health professionals as "just part of being a woman," driving them towards isolation and hopelessness and even leading some to consider suicide.

Minimized symptoms

Even when women seek help, evidence shows many concerns are overlooked and dismissed, and they are more likely to be stereotyped as exaggerating or being over-emotional in healthcare settings. This implicit bias does not depend on the gender of the healthcare professional. Evidence shows that women are less likely to receive aggressive treatment

"People think I'm being dramatic when in reality, my reaction is proportional to the pain I'm experiencing. At times I'm not able to even get out of bed."

- Survey respondent suffering from painful periods

when diagnosed and are more likely to have their pain characterized as "emotional," "psychogenic," and therefore "not real." This concept has been termed the "Gender Pain Gap" and is worse for Black women, Indigenous women and women of colour.

The Consequences of Making Women's Health Issues "Taboo"

Limited specialist knowledge and treatment options

Health conditions that disproportionately or solely affect women are understudied, which impacts the knowledge and tools available to healthcare providers. In Alberta, only 3.4% of health research funding goes to women's health research, leading to well-meaning medical professionals being under-informed and ill-prepared to offer effective solutions and support. Many women in the survey even reported accessing care outside of Canada for their conditions.

"Hormonal shifts again make it hard to function 100%, I'm in an executive leadership role, and I need to be on top of my emotions and mental game, and there are some days I simply cannot."

- Survey respondent suffering from perimenopause

Domino effect on mental + physical health

The mental and physical consequences of the symptoms, empathy gap, dismissal, and delayed diagnosis are compounded. Many conditions, if untreated, are also linked to long-term health issues, such as high blood pressure, cardiovascular disease, type II diabetes, depression and anxiety. Studies have shown depressive symptoms in 87% of endometriosis patients and anxiety in 88%. Even more concerning, a recent study found that 50% of women with endometriosis had suicidal thoughts.

"I have to take opioids on a daily basis to keep the pain at bay. It all seemed like a domino effect that resulted in many symptoms like fibromyalgia, arthritis, high blood pressure, depression, anxiety and panic disorder."

- Survey respondent suffering from endometriosis

Impacted work and careers

The taboo around pivotal aspects of women's physiology has a significant impact on the working life of women, explored in the three M's: menstruation, maternity, and menopause. In Alberta, many health concerns explored significantly impacted women's work lives. For women with endometriosis, painful periods, pelvic floor issues, perimenopause and menopause, between 50-90% of women reported significant work and career impact. Approximately 10% of women are believed to stop working because their perimenopausal symptoms are debilitating.

The Consequences of Making Women's Health Issues "Taboo"

Impacted home life

Impacts are not isolated to work; women in Alberta reported significant effects at home, from missing social events and being unable to play with children to harmed friendships, romantic relationships and marriages. For those suffering from endometriosis, painful periods, pelvic floor dysfunction, perimenopause and menopause, 80% of women reported significant impacts on their home lives.

"It has been incredibly frustrating and time-consuming to even find a doctor who will listen, never mind one who is equipped to help."

- Survey respondent suffering from endometriosis

Compounding inequities

In addition to taboos, many women, particularly Indigenous women, face additional barriers of discrimination and racism. Lack of culturally-appropriate and trauma-informed care adds to the distrust of the healthcare system, linked to the use of healthcare control and contain Indigenous populations.

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"It makes me less interested in sex, and the stress it causes puts me in a bad mood, leading to fights between me and my partner. He also had to take care of me and take me to appointments when I was dealing with cervical precancer."

- Survey respondent suffering from sexually transmitted infections/diseases

"The lack of support, understanding and research is heartbreaking."

- Survey respondent suffering from PMDD

"Mentally it's exhausting having yet another thing wrong with your body and the itch is insane. It's a disruption from day-to-day activities, work, exercise and the bedroom. A destroyer of marital relations."

- Survey respondent suffering from recurrent yeast infections or bacterial vaginosis

What Can You Do About It

With more research, greater awareness, early detection, and effective and comprehensive management, we believe we can collectively reduce the impact of these conditions on the health of women in our province. How can you play your part?

- 1. Talk with your healthcare provider about your health concerns.**
 - Bringing an ally or advocate to healthcare appointments can create emotional support and validation for those experiencing the implicit gender bias of healthcare systems.
- 2. Find a specialist organization for community support.**
 - Research indicates that women participating in community health groups are significantly more likely to increase self-advocacy with healthcare providers and exhibit confident navigation of health services.
- 3. Encourage conversation with your friends and family.**
 - Research has shown that talking openly helps. For example, research shows that in households where people speak openly about periods, young women feel more supported, confident and less awkward than in homes that do not.
- 4. Be an ally.**
 - Increase your knowledge about women's health conditions, particularly those experienced by your friends and family. Check your implicit biases in evaluating their health concerns.
- 5. Fund research to uncover more about these conditions.**
 - With only 3.4% of health research funding going to women's health, a 17-year time lag from medical research to clinical practice, and the evident lack of research, knowledge and treatments, we must fund critical research into these areas.

Women's Health Speed Reads

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To raise awareness about common, yet taboo, women's health issues, the AWHF has put together the following overviews or 'speed reads' that provide insight into specific conditions affecting women in our province, the prevalence, challenges and impacts, and resources for further support.

While many conditions were covered in our report, we chose to highlight these five main condition areas as they represent health areas where inspiring research is already happening, and where we expect we can make the most impact in the near future.

Our hope is that by reviewing these sections, you will come away with a deeper understanding of the scale and impact these conditions currently have on women, and how we can make a difference together going forward.

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**Premenstrual
Dysphoric
Disorder**

Painful Periods and Premenstrual Dysphoric Disorder (PMDD)

68%

of women reported experiencing
painful periods and menstrual cramps

12%

reported PMDD

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Definition

Dysmenorrhea is the medical term for painful menstrual periods caused by uterine contractions. Symptoms associated with dysmenorrhea include gastrointestinal symptoms such as nausea, bloating, diarrhea, constipation, vomiting, and indigestion. Also, irritability, headache, and low back pain are prevalent among women presenting with primary dysmenorrhea. Tiredness and dizziness are also associated with dysmenorrhea.

PMDD is a severe premenstrual syndrome related to hormone changes during menstrual cycles. Symptoms include mood swings, depression, irritability or anxiety, sore breasts, bloating and joint or muscle pain for one to two weeks before menstruating.

Prevalence

Dysmenorrhea, or painful menstrual periods, is one of the common gynecological problems among all women, regardless of age or race. The prevalence of painful periods can vary between 16% and 91% in women of reproductive age, and life-impacting moderate-to-severe dysmenorrhea is reported by about one-third of women. In Alberta, 68% of women reported experiencing painful periods, and 12% had PMDD.

Between 3-8% of women, transgender men and non-binary individuals of reproductive age suffer from PMDD, with as many as 500,000 individuals across Canada. Yet, an estimated 90% of sufferers are thought to be undiagnosed.

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Painful Periods and Premenstrual Dysphoric Disorder (PMDD)

Challenges and Impacts

The stigma around periods and knowledge of what is “normal” often leads to a delay in seeking medical advice for issues associated with menstruation. Furthermore, evidence of misdiagnosis, minimized symptoms and dismissal from healthcare providers compound the delay in diagnosis. Both conditions are associated with significant impairment in quality of life, whether physical or mental. Painful periods are associated with considerable impairment in quality of life between 16% to 29% of women, and in adolescents, 12% of the monthly school and work activities are lost due to absenteeism because of painful periods. Yet improvement of health-related quality of life through symptom control and management has shown to be successful for PMDD and menstrual cramps.

In Alberta, painful periods were the top identified issues that greatly impacted women’s lives, with 86% suggesting impacts to work life and 80% of those experiencing this condition affecting home life. Yet only 55% of women in Alberta felt that friends and family support them regarding this issue.

“Feeling like it’s too painful to do literally anything but that no one actually understands. Other women who don’t have this issue think you’re faking it, and men tend to just not want to know about it.”

- Survey respondent suffering from painful period

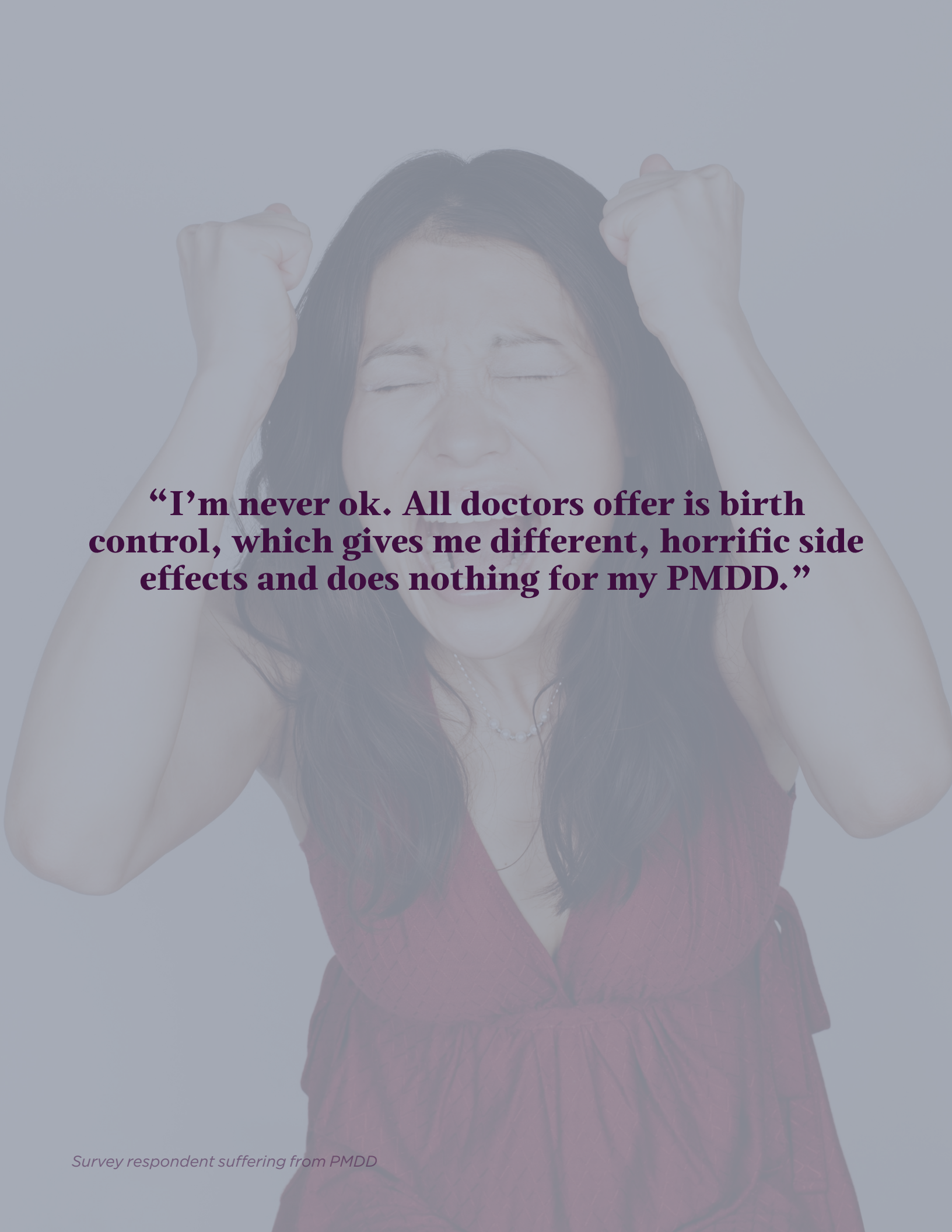
“It is the level of pain that can remove you from participating in all aspects of life. From a class or activity at school where you are severely distracted from a subject or event due to painful cramp distractions, to feelings of overwhelming pain that keep you from focusing on important people in your life to enjoying special events or everyday life.”

- Survey respondent suffering from painful period

Support

Your Period offers facts and resources on menstruation from Canada’s experts at the Society of Obstetrics and Gynecology of Canada.

The International Association for Premenstrual Disorders (IAPMD) is an American organization offering tools and educational resources, a digital symptom tracker, and peer support opportunities for conditions including PMDD.



“I’m never ok. All doctors offer is birth control, which gives me different, horrific side effects and does nothing for my PMDD.”

Survey respondent suffering from PMDD

Menopause



Perimenopause and Menopause

39%
of women reported experiencing menopause

31%
experienced perimenopause

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Definition

Menopause is the time in a woman's life when their ovaries stop producing the hormones estrogen and progesterone, and they stop menstruating. The average age of menopause in Canada is 51.5. Perimenopause means "around menopause" and refers to the time during which women's bodies make the transition to menopause. It is also referred to as the menopausal transition. Symptoms include a change in periods, hot flashes, night sweats, trouble sleeping, vaginal dryness, mood swings and trouble focusing.

Prevalence

In Canada, 90% of women are menopausal by the age of 55-56, but for 5%, it occurs between the ages of 40-45 and many women who need surgery or chemotherapy are forced into early-onset menopause. A wide range of symptoms are reported by 84% of women at some stage of perimenopause.

In Alberta, 31% of women reported experiencing perimenopause and 39% menopause.

"From being dismissed by a female doctor as something you just need to get through to really not being informed about what my mind and body would be going through. It's only now we are somewhat talking about it. From frustration to hopelessness, depression, rage and a feeling sometimes of despair."

- Survey respondent suffering from perimenopause/menopause

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Perimenopause and Menopause

Challenges and impacts

There are frequent misconceptions about menopause and perimenopause; specifically, there is little awareness of the

“It’s very weird and I have no idea about what is going on with my body and reproductive health. My periods are irregular, I don’t know if they’re normal, my sleep is irregular at best, I’m tired, my moods are out of whack, and there is very little information out there for me. It’s very stressful.”

- Survey respondent suffering from perimenopause/menopause

symptoms and understanding of the stages. In Alberta, 56% of non-self-identifying women in our survey report knowing someone who has experienced menopause, but only 15% report knowing someone who has experienced perimenopause.

While 66% of women in perimenopause seek medical care, a treatment delay is

reported by 53% of perimenopausal women, and only 16% report effective treatment.

Menopause and perimenopause have a significant impact on both women’s work and personal lives. In Alberta, over 73% of women experiencing perimenopause and 52% experiencing menopause report it impacting their working life. Broader data suggests that 10% of women will stop working because their symptoms are debilitating. At home, 80% and 60% of women report that perimenopause and menopause have affected their personal life, respectively, and only 55% feel supported by friends and family.


Support

The Menopause Clinic at Lois Hole Hospital for Women aims to address the concerns of women managing their menopausal symptoms and provides a full spectrum of services.

Menopause And U offer facts and resources on menopause from Canada’s experts at the Society of Obstetrics and Gynecology of Canada.

The Menopause Foundation of Canada (MFC) is an advocacy organization created to raise awareness of the impact of menopause on women and society.

Menopause Chicks is an online community that empowers women to easily and confidently navigate perimenopause and menopause.



“I am a miserable wreck. I don’t ever remember being so anxious and irritable in my life. I don’t know if the pains I have are normal aging, perimenopause or some unknown fatal illness. It’s awful. I feel invisible.”

Survey respondent suffering from perimenopause/menopause

**Pelvic Floor
Dysfunction**

Pelvic Floor Dysfunction

40%

of women reported experiencing some form of pelvic floor dysfunction

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Definition

Pelvic floor dysfunction refers to a broad range of symptoms and bodily changes related to abnormal function of the pelvic floor muscles. These symptoms include bladder or bowel incontinence and pelvic organ prolapse.

Prevalence

Approximately 23% of women experience at least one form of pelvic floor disorder, which increases incrementally with age, ranging from 10% in women between the ages of 20 and 39, to 50% in those aged 80 or older. These conditions also increase significantly for women who have given birth; for example, pelvic organ prolapse will affect 50% of women who have had children in their lifetime, occurring right after childbirth or many years later. In our survey, 40% of women report pelvic floor dysfunction, including prolapse and incontinence.

“I have to arrange my life around the symptoms; I often cancel social occasions or days out of the house to shop because of it. It also played a huge role in my decision to retire.”

- Survey respondent suffering from pelvic floor dysfunction

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Pelvic Floor Dysfunction

Challenges and impacts

Many studies suggest that because many pelvic floor conditions are considered “part of life,” women feel stigmatized, guilty, and ashamed; it restricts their participation in activities and negatively influences sexual relationships and satisfaction. Many individuals do not seek help due to the taboo and stigmatizing nature of the condition. In Alberta, 57% of women report pelvic floor concerns impacting their working life and 68% their home life. And when they do seek health, the physical and psychological impacts of delays in treatment are substantial.

“It is impossible to be taken seriously or get a real diagnosis by anyone, which is the most frustrating part of the whole process. I’ve bounced around from my GP to gynecologist to physiotherapist to dermatologist.. each time I’ve had to advocate for myself, and each time I’ve had next to zero resolution or care.”

- Survey respondent suffering from pelvic floor dysfunction

In Alberta, while 70% of women with pelvic health concerns seek medical care, 54% experienced a delay in receiving treatment or care, and 56% of women have had to pay out of pocket for treatment. Yet once they received treatment, most women reported it being effective.

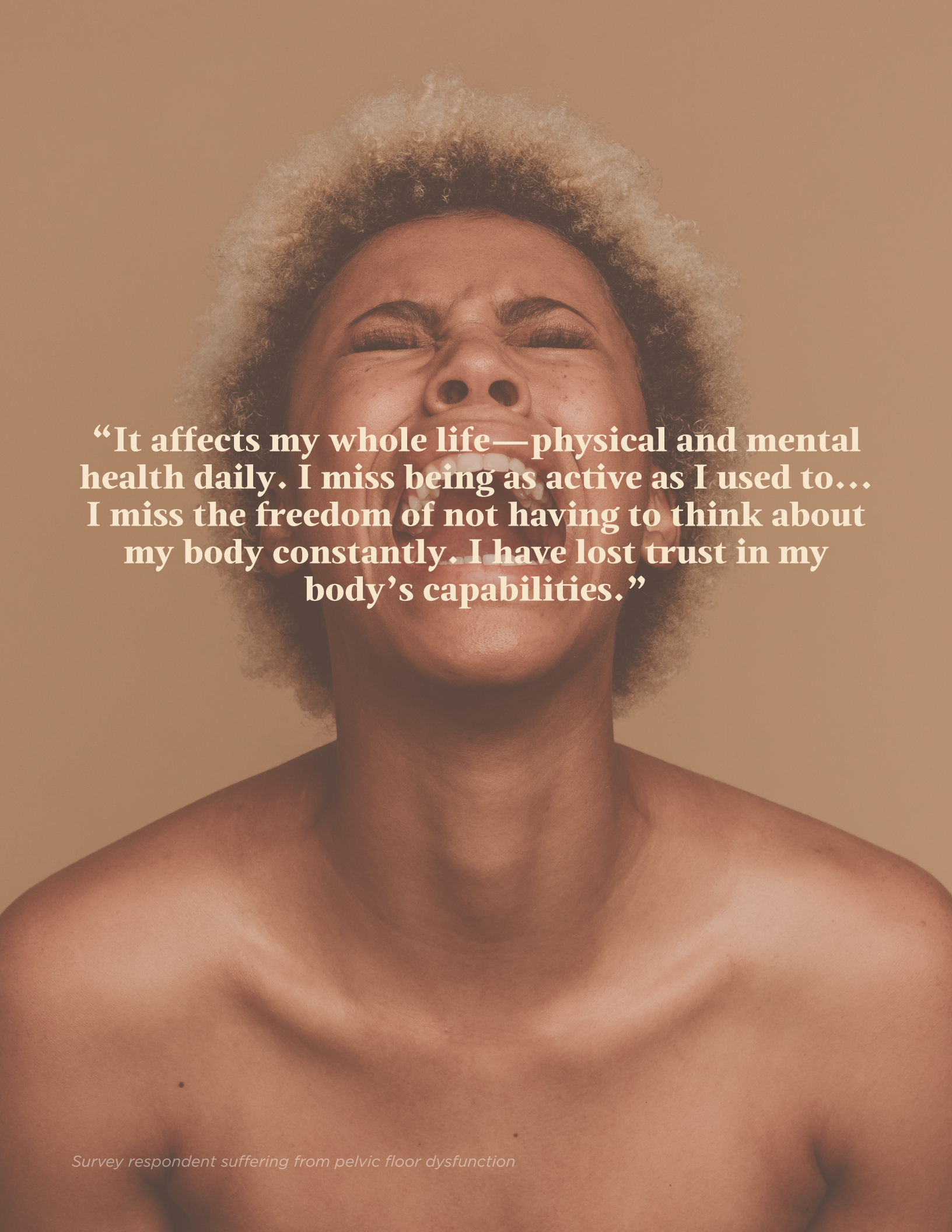
Support

Urogynecology Wellness Clinic at Lois Hole Hospital supports patients with pelvic organ prolapse and incontinence. Services include education, behavioural treatment, medical and surgical interventions, and physiotherapy.

The Canadian Continence Foundation is a non-profit and registered charity, established in 1986, dedicated to helping people experiencing urinary and bowel incontinence to confidently seek and access cures, remedies and treatment options.

National Association for Continence is an American non-profit organization dedicated to education and advocacy, with access to online forums.

Urology Care Foundation focuses on research and providing current, comprehensive, reliable urologic information.



“It affects my whole life—physical and mental health daily. I miss being as active as I used to... I miss the freedom of not having to think about my body constantly. I have lost trust in my body’s capabilities.”

Survey respondent suffering from pelvic floor dysfunction

Endometriosis



Endometriosis

17%
of women reported experiencing endometriosis

AWHF

Definition

Endometriosis is a disease where cells of the uterine lining grow at sites outside the uterus. It can be asymptomatic, mild, or a disabling condition causing severe pain. The classic symptoms of endometriosis are very painful menstruation (dysmenorrhea), heavy menstrual bleeding, irregular periods, painful intercourse (dyspareunia), bloating, diarrhea, constipation, fatigue, and infertility.

Prevalence

Endometriosis affects approximately 1 million people in Canada. It mainly affects women of reproductive age, with a prevalence of about 10%, and unmeasured numbers of transgender, non-binary and gender-diverse individuals. In Alberta, 17% of respondents had experienced endometriosis.

“It has left me extremely anxious to talk to doctors about anything as I am terrified of not being believed or listened to, misdiagnosed or spoken to with contempt. The way the medical system and doctors have treated me and dismissed me is the worst part.”

- Survey respondent suffering from endometriosis

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Endometriosis

Challenges and impacts

Sadly endometriosis is associated with extensive diagnostic delays. In Canada, these vary, with an average of 5.4 years to diagnosis, with over a 3-year delay from onset of symptoms to physician consultation and a 2-year delay between physician consultation and diagnosis. These delays are associated with a lack of awareness; in Alberta, only 4% of respondents believe that people are familiar with endometriosis, and only 30% of women respondents with endometriosis are likely to know others with the same condition. The wide-ranging symptoms and dismissal by healthcare professionals also contribute to delayed diagnosis. In Alberta, 40% of respondents with endometriosis reported seeking care from 5-10 healthcare providers for this condition. While many women reportedly shared their diagnosis with other people, the level of support by friends and family is limited.

Endometriosis and associated symptoms have been shown to have considerable impacts on educational attainment, work productivity, career choices and success, impair social life and activities, affect family choices, negatively impact mental and emotional health and adversely affect one's quality of life. In Alberta, 86% of those with endometriosis reported that the condition affected their home life, and 89% said effects on their work life.

Support

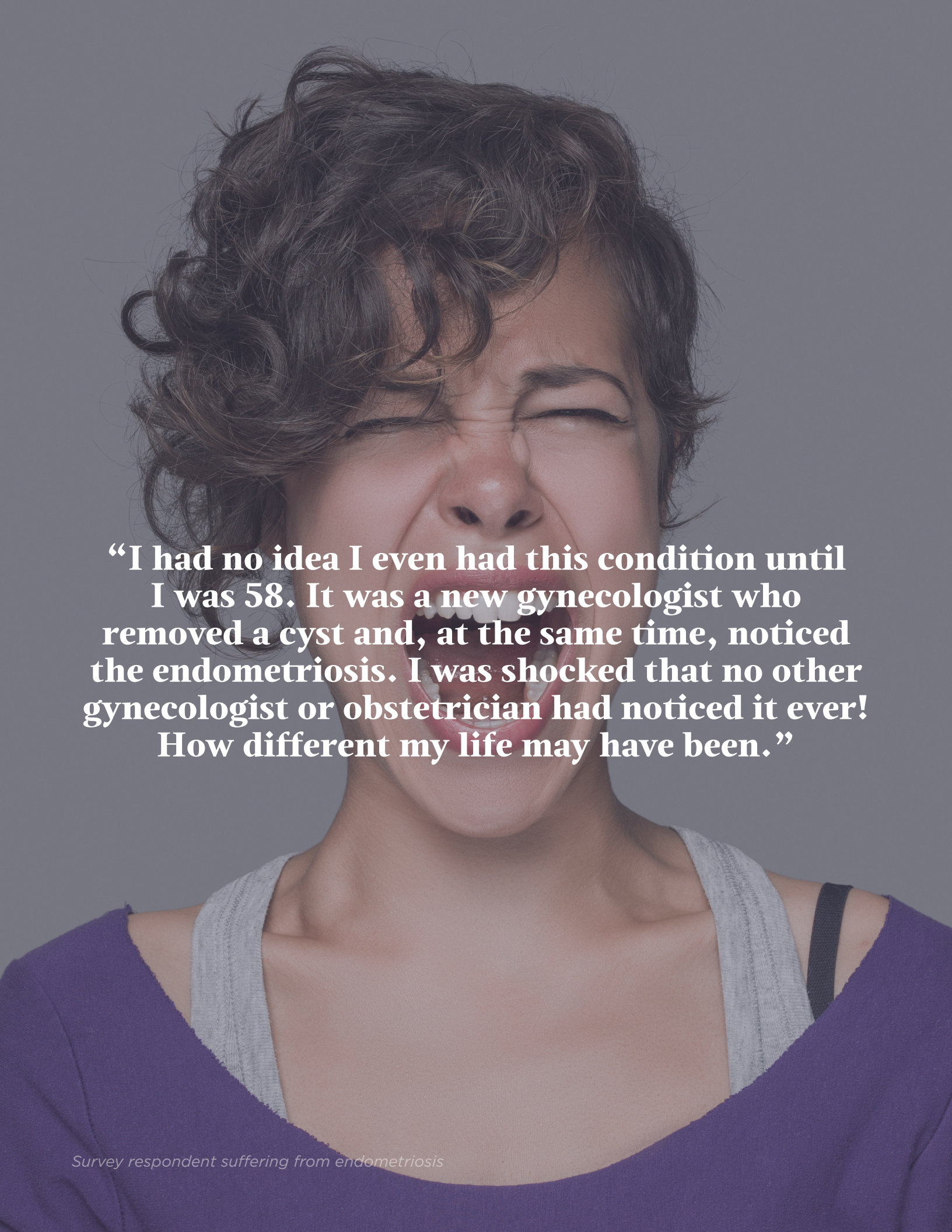
Endometriosis Network Canada provides comprehensive details on symptoms, diagnosis and treatment in addition to wellness and support resources, including a facilitated online support group.

EndoAct Canada is a collective of patients, clinicians, and researchers dedicated to people with endometriosis, providing

resources such as an advocacy toolkit and shared stories.

“Endometriosis is extremely life altering. It is hard to keep a job when you are constantly in pain. It's hard to make plans. It's hard to do anything because you never know what each day is going to be like. On top of that, every doctor mistreats you, and it is so degrading and scary that there's minimal help.”

- Survey respondent suffering from endometriosis



“I had no idea I even had this condition until I was 58. It was a new gynecologist who removed a cyst and, at the same time, noticed the endometriosis. I was shocked that no other gynecologist or obstetrician had noticed it ever! How different my life may have been.”

Survey respondent suffering from endometriosis

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**Polycystic
Ovary
Syndrome**

Polycystic Ovary Syndrome (PCOS)

9%

of women reported experiencing polycystic ovary syndrome

AMHF

Definition

Polycystic ovary syndrome (PCOS) is a condition in which a woman has increased levels of male hormones which presents with the following symptoms: menstrual irregularities, infertility, skin problems such as acne and increased hair growth, increased number of small cysts in the ovaries, and other hormonal related issues such as obesity.

Prevalence

It is estimated that PCOS affects 8-13% of women of reproductive age, so as many as 1.4 million Canadian women may be afflicted with PCOS. In our survey, 9% of self-identified women reported experiencing PCOS.

“I was told I would only be treated for fertility issues related to PCOS. Nothing else.”

- Survey respondent suffering from PCOS

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Polycystic Ovary Syndrome (PCOS)

Challenges and impacts

Like many other women's health issues, diagnostic delays and dismissal have affected many women with PCOS. In one study, over

“Multiple Drs were very dismissive. It wasn't until I went to the third fertility doctor that I was diagnosed, and at that point, it was beyond assistance.”

- Survey respondent suffering from PCOS

one-third of respondents waited for more than two years, and 41% saw three or more doctors before attaining a diagnosis. Comprehensive research by Dr. Donna Vine from the University of Alberta and a WCHRI researcher suggests that 34% of women took more than two years to get a diagnosis of PCOS, and 60% had to visit more than one healthcare provider before

a final diagnosis. Three-quarters were not told about the long-term medical health risks linked to PCOS, such as cardiovascular diseases. Mental health impacts are often unaddressed in doctor's visits, and many are just treated for their reproductive and fertility issues. In Alberta, many women reported considerable effects on their self-esteem and mental health, school work and career because of pain, and many documented stories of dismissal and delayed diagnosis.


Support

PCOS Together was founded by WCHRI researcher Dr. Donna Vine with a mission to improve our understanding of health outcomes and healthcare in women with and without PCOS. It provides information about research, online community forums and resources to support people advocating for themselves in healthcare appointments.

PCOS Awareness Association is a non-profit organization dedicated to raising awareness of PCOS worldwide, providing education and support services to help people understand and obtain treatment for the condition.

“It has had a huge impact. Loss of school and work due to pain, [and] because of late diagnosis [PCOS] caused infertility, miscarriages, and eventually a hysterectomy. I was told it was all in my head, not that bad, I was exaggerating, and it was because of my weight until I thought I was actually going insane.”

- Survey respondent suffering from PCOS

A close-up portrait of a woman with long, wavy hair dyed in shades of teal and purple. She has a frustrated or angry expression, with her mouth wide open as if shouting or crying out. Her eyes are squinted, and her eyebrows are furrowed. The background is a plain, light-colored wall.

“I was in my early teens when I started having pain and tried to get help, I was in my 30s when I was finally diagnosed.”

Survey respondents suffering from PCOS

Methods

The Alberta Women’s Health Foundation tasked Y Station with conducting a general population survey through the Y Station Engage panel and a web link invitation. Data collection occurred between July 11, 2022, and August 2, 2022. The purpose of the survey was to understand the unique challenges of women’s health in Alberta and, particularly, women’s gynecological health. A total of 2,229 respondents completed the survey, with 91% of survey respondents identifying as women.

All quotes within the report are verbatim or with marked adjustments for ease of comprehension. They are derived from responses provided by survey participants.

Supplementary academic and grey literature was obtained to provide broader context and details on health issues, experiences and inequities.

Recommended citation: Alberta Women’s Health Foundation (2023) “Surveying the Silence: Exploring the impact of taboos in women’s health.”

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- All respondents that participated in our online survey. Thank you for openly and honestly sharing your experiences.
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- [Organon](#), for their paradigm-shifting sponsorship of this report and strategic partnership in supporting the AWHF, helping amplify the voices of women across Alberta and also the globe while taking us toward a better and healthier every day for every woman.
- The donors and supporters of the Alberta Women's Health Foundation that continue to give generously to support the health of women in our province.
- [Y-Station](#), which delivered research insights into the experiences of women throughout the province.
- Researchers and staff at the [Women and Children's Health Research Institute](#) (WCHRI) for their world-leading research dedicated to better understanding women's health.
- The staff and Board of the Royal Alexandra Hospital Foundation and Alberta Women's Health Foundation, who are unwavering in their dedication to improving women's health in Alberta through fundraising, awareness, and advocacy work.

The AWHF - Who We Are

AWHF

We stand for women and women's health.

Disease is not restrained by borders. Fortunately, neither is the knowledge that comes from research. The new initiative of the Royal Alexandra Hospital Foundation has been created to fill urgent gaps in women's health research, an area historically underfunded and, sometimes, nonexistent. Excellent health outcomes are the direct result of ongoing investment in health research. Our mission is to foster equity in women's health, close research gaps, and connect pathways from lab to life, all of which advance clinical care at the Lois Hole Hospital for Women and other women's health centres across Alberta and beyond.

In partnership with
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Visit us at AlbertaWomensHealthFoundation.org and help us to

#RefocusTheResearch

Please use the hashtag **#SurveyingTheSilence** in any posts referencing this report or the data contained within it.

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