



# Submission cover sheet

## Inquiry into endometriosis and other pelvic pain conditions

Submission number: 033

Submitter: Women with Disabilities ACT

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## **Submission to the Inquiry into endometriosis and other chronic pelvic pain conditions**

**17 April 2026**

## About WWDACT

Women with Disabilities ACT (WWDACT) is a systemic advocacy and peer support organisation dedicated to advancing the rights, safety, and inclusion of women, girls, non-binary and gender diverse people with disabilities in the ACT region. Established in 1995, WWDACT's work is underpinned by a human rights philosophy, aligning closely with the Convention on the Rights of Persons with Disabilities (CRPD) and the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW). WWDACT is unique in its intersectional approach to gender and disability advocacy, utilising co-design principles and lived experiences of members to influence policy and drive systemic change. As a Disabled People's Organisation, we are run by and for women and non-binary people with disabilities.

WWDACT is a founding member of the ACT Disability Directed Consumer Caucus – a policy alliance of organisations representing Canberrans with Disabilities, including Advocacy for Inclusion and ACT Down Syndrome and Intellectual Disability. The Caucus represents our commitment to shared advocacy and representative work to the ACT Government on some key issues and matters of practice.

## About this submission

This submission was prepared by Women with Disabilities ACT (WWDACT). The contents of the submission was also informed by discussions with Women's Health Matters and includes unpublished survey data from their Survey of Women's Health (2025). This submission is endorsed by Women's Health Matters.

WWDACT endorses the submission made to this inquiry by Women's Health Matters and echoes their evidence-based recommendations, particularly the primary recommendation to develop an integrated, publicly funded pelvic health system in the ACT.

As part of preparation for this submission WWDACT conducted our own consultations via a survey. We received 22 complete survey responses from women, non-binary and transgender people with disabilities who had experience with endometriosis or other pelvic pain conditions. The survey received responses from people who attended WWDACT events in person and online during March 2026, who were subscribed to the WWDACT newsletter, or who follow WWDACT on social media.

Of the survey respondents, just over half had a formal diagnosis of endometriosis, around a third had a formal diagnosis of adenomyosis. A third had a formal diagnosis of polycystic ovarian syndrome (PCOS). Other conditions mentioned by survey respondents which may cause or contribute to chronic pelvic pain include pelvic floor dysfunction, IBS, fluid build up in fallopian tubes, a decidual cast, pelvic myalgia, pelvic congestion syndrome, lichen sclerosis, dyspareunia, and vulvodynia. Around 60% of respondents indicated they had multiple conditions contributing to chronic pelvic pain, whether diagnosed or undiagnosed.

This submission includes our responses to a number of the terms of reference for the inquiry. The submission also includes a de-identified case study of a WWDACT member, 'Lisa', to highlight the impact of chronic pelvic pain on individuals. Recommendations for changes that could be made to support people with endometriosis and chronic pelvic pain conditions are included and summarised at the end of the submission, suggested and supported by survey respondents.

## Response to terms of reference

### 1. The number of women and other people in the ACT who suffer from endometriosis, adenomyosis, polycystic ovarian syndrome and other chronic pelvic pain conditions

In their submission to this inquiry, Women's Health Matters drew on data from their Survey of Women's Health (2023, 2025) to infer the likely prevalence of people with endometriosis, adenomyosis, polycystic ovarian syndrome (PCOS) and other chronic pelvic pain conditions. A significant number of respondents who identified that they had ever been diagnosed with these conditions also identified as people with disabilities.

For example, in the 2025 Survey of Women's Health:

- 28.1% of women with disabilities had ever been diagnosed or treated for endometriosis or adenomyosis
- 19.3% of women with disabilities had ever been diagnosed or treated for PCOS
- 30.8% of women with disabilities had experienced persistent pelvic pain in the past 2 years

The majority of respondents to WWDACT's survey conducted in March this year outlined that they consider chronic pelvic pain, endometriosis and other conditions to be a disability (over 60%). However, most respondents also had other conditions or disabilities, aligning with the increased likelihood of women and gender diverse people to have multiple co-occurring disabilities<sup>1</sup>. The impacts of endometriosis and chronic pelvic pain conditions compound with other co-occurring disabilities for many women and non-binary people in the ACT.

The data shows that the impacts of endometriosis and chronic pelvic pain conditions are felt particularly strongly by women with disabilities,

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<sup>1</sup> Australian Institute of Health and Welfare (2021). "Chronic condition multimorbidity: What is multimorbidity and how common is it?". Australian Institute of Health and Welfare. <https://www.aihw.gov.au/reports/chronic-disease/chronic-condition-multimorbidity/contents/what-is-multimorbidity-and-how-common-is-it>

and is likely to be a significant issue for close to a third of women, non-binary and gender diverse people in the ACT who identify as having a disability/disabilities.

## 2. The barriers in the ACT to getting a diagnosis and gaining access to treatment including primary care, specialist clinics and ongoing pain management for these conditions

Overwhelmingly, for our survey respondents the biggest barrier to getting a diagnosis and getting access to treatment was cost. A majority of survey respondents brought up cost as a major barrier.

Costs for getting a diagnosis and accessing treatment are significant, and add up for people accessing multiple professionals on their pathway to receiving care. Typical experiences included:

- Multiple visits to a GP, only partially subsidised by Medicare (it is difficult to access a bulk-billed GP appointment in the ACT, as only 9 clinics provide free appointments for anyone with a Medicare card according to research conducted by the ACT Greens<sup>2</sup>)
- Referrals to allied health professionals e.g. pelvic physiotherapy
- Referrals to specialists, often accessed in the private system due to long wait times in the public system
- Referrals to ultrasounds (with many respondents paying for 3 ultrasounds to get a diagnosis of endometriosis)
- The potential for multiple appointments with GPs and specialists to get a second or third opinion, due to gender and disability bias from healthcare professionals (see section 3)
- Payment for surgery if required – one respondent mentioned they paid \$8,000 for a laparoscopy
- Payment for medications such as contraceptive pills to manage pain, often not on the PBS and requiring payment out of pocket

The financial burden across these interactions with the medical system is immense, and many survey respondents mentioned they had paid thousands out of pocket to access diagnosis and treatment for their

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<sup>2</sup> ACT Greens (2026). "Free doctor visits in the ACT". ACT Greens. <https://greens.org.au/act/freeGPs>

endometriosis or chronic pelvic pain. Several mentioned that they needed to rely on family or friends for help to cover medical costs, and one mentioned that they needed to borrow money.

The cost of ongoing pain management (e.g. continuous use of contraceptive pills not on the PBS, or accessing allied health professionals) is very high.

Women and non-binary people with disabilities are already more impacted by financial burden and are more likely to be struggling financially than people without disabilities. This is due to multiple reasons, including but not limited to being more likely to work part time, and less likely to be in the workforce at all<sup>3</sup>, less likely to receive access to supports such as the NDIS<sup>4</sup>, likely to spend significant amounts on healthcare<sup>5</sup>, and more likely to experience financial control and abuse<sup>6</sup>. The cost of managing disability and chronic health conditions, including endometriosis and chronic pelvic pain, is more likely to be prohibitive for people already experiencing financial strain.

Respondents also mentioned the significant wait times to access diagnosis and treatment. The wait times in the public system in the ACT are prohibitive in many cases, forcing people to go private to gain access to care. Respondents also faced push-back from doctors, with many GPs preferring to 'wait and monitor symptoms' before making referrals.

A majority of respondents faced discrimination with GPs not believing them, further delaying their access to care. One person was declined

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<sup>3</sup> Australian Bureau of Statistics (2018). "4430.0 – Disability, Ageing and Carers, Australia: Summary of Findings, 2015" (statistics release). Australian Bureau of Statistics. <https://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4430.0Main+Features1022015?OpenDocument>

<sup>4</sup> Australian Institute of Health and Welfare (2024). "People with Disability in Australia 2024: Summary fact sheet 3: Social Support". Australian Institute of Health and Welfare. [https://www.aihw.gov.au/getmedia/36e64481-2fe4-4c03-bf35-d1f12ebac35a/aihw-dis-72-2024\\_fact-sheet-03\\_social-support.pdf](https://www.aihw.gov.au/getmedia/36e64481-2fe4-4c03-bf35-d1f12ebac35a/aihw-dis-72-2024_fact-sheet-03_social-support.pdf)

<sup>5</sup> Olney, S and Yates, S (2025). "The Costs of Living With Disability in Australia: Accounting for Variable Disability-Related Deprivation in Poverty Measures". *The Australian Economic Review* 58(S1):S36-S44. <https://onlinelibrary.wiley.com/doi/10.1111/1467-8462.70017>

<sup>6</sup> McGowan, J, Maher, J, Malowney, T and Thomas, K (2019). *Identifying economic abuse amongst women with disability in Victoria: A toolkit for service providers and people affected by family violence (Final Report)*. Monash University. [https://anrows.intersearch.com.au/anrowsjspui/bitstream/1/20487/1/Identifying\\_economic\\_abuse\\_amongst\\_women\\_with\\_disability\\_in\\_Victoria\\_Final\\_Report.pdf](https://anrows.intersearch.com.au/anrowsjspui/bitstream/1/20487/1/Identifying_economic_abuse_amongst_women_with_disability_in_Victoria_Final_Report.pdf)

further care, even after having a cyst ruptured in hospital. Many mentioned needing to see multiple GPs, gynaecologists and other specialists before getting access to diagnosis or treatment. (See section 4).

The impact of compounding gender and disability discrimination results in women with disabilities reporting that medical professionals often do not take them seriously – and experiencing mistreatment such as diagnostic overshadowing. This experience is common for women with disabilities interacting with the healthcare system (see WWDACT's previous submission to the Inquiry into ACT Health System data, demand and processes)<sup>7</sup>, and is exacerbated for issues related to chronic pelvic pain due to the gendered nature of this issue.

GPs are often the first point of contact for people trying to access treatment for chronic pelvic pain, and being disbelieved by a GP is a barrier to accessing referrals to specialists or allied health professionals.

The combination of wait times and the impacts of medical discrimination can produce a significant barrier to women with disabilities accessing diagnosis for their pelvic pain. Around a third of our respondents waited over 10 years for a diagnosis, up to 33 years for one survey respondent.

Being disbelieved about the severity of pain precludes access to life-changing pain killers that enable people experiencing chronic pelvic pain to have a better quality of life. Many survey respondents reported that doctors would refuse to prescribe anything and would recommend paracetamol or ibuprofen, even after pelvic surgery.

For some survey respondents, a history of past trauma prevented their access to care (e.g. being unable to access pelvic physiotherapy as a treatment option, or being only able to access female doctors). Women with disabilities as a cohort are more likely to have experienced sexual violence and the impacts of trauma<sup>8</sup> that may cause barriers to accessing care for pelvic pain.

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<sup>7</sup> <https://wwdact.org.au/submission-to-the-inquiry-into-act-health-system-data-demand-and-processes/>

<sup>8</sup> <https://pwd.org.au/wp-content/uploads/2021/07/Women-with-Disability-and-Domestic-and-Family-Violence-A-Guide-for-Policy-and-Practice.pdf>

Some survey respondents mentioned that they were on the pill continuously to manage pain despite unwanted side-effects. Many sought other contraceptive or hormone therapies e.g. IUDs only to find these exacerbated pelvic pain, and then pain was dismissed as a direct result of the contraceptive device rather than being assessed for further issues such as endometriosis.

Many respondents outlined that treatment options had significant impacts – they could be life threatening, traumatic, involve surgical intervention, unwanted side-effects. For some respondents cultural reasons prohibited treatment options such as pelvic physiotherapy.

Being non-binary and needing to access gendered services for ‘women’ also brought up gender dysphoria and is a further barrier to accessing treatment.

#### **Respondent recommendations**

Addressing the **cost barrier to diagnosis and treatment** will have an overwhelming impact on accessing care for women and non-binary people with endometriosis and chronic pelvic pain.

Suggestions for addressing this barrier include:

- Increasing the range of treatments subsidised under the PBS or other schemes
- Increased rebates for medical practitioners to lower the out-of-pocket cost for patients
- Subsidised longer appointments at GPs, and incentivising more practices to bulk bill in the ACT

### 3. [The treatment options and supports available in the ACT compared to other jurisdictions, their evidence-based effectiveness and potential side effects and impacts](#)

Although the stories shared to us by women and non-binary people with disabilities have not given us a full picture of the treatment options available in the ACT, it is clear that the extent and access to supports within the ACT is limited compared to other jurisdictions. Multiple survey

respondents indicated that they travelled to other jurisdictions (Sydney or Melbourne) for part or all of their diagnosis and treatment journey. 6 respondents had to travel to Sydney for diagnosis or treatment.

The waiting times for professionals in the public and private system in the ACT lead to inequalities in accessing supports. For many women and non-binary people with disabilities, they are unable to go interstate for treatment due to factors like inability to drive, prohibitive costs of travel due to fuel or accommodation, and a lack of support systems in a different city.

Improving the range and accessibility of supports, especially public supports, available in the ACT will be essential in ensuring timely access to diagnosis and treatment.

### **Respondent recommendations**

Survey respondents made several suggestions **to improve access to diagnosis and treatment options within the ACT**. These included:

- Incentive programs for gynaecologists and other specialists to practice and offer procedures within the public system
- Funding additional specialised pelvic ultrasound clinics, in addition to CFAC in Bruce
- Funding to increase the number of specialists practicing in the ACT
- Funding to improve access to specialist diagnostic tools, such as specialist endometriosis ultrasounds
- Increasing funding and capacity of pelvic physiotherapists within the ACT Health public system
- Provide subsidies for laparoscopy surgeries performed locally in Canberra, for people who cannot afford access through the private system
- Increase number of specialists located centrally in Canberra to improve access to those reliant on public transport
- Pilot multi-disciplinary clinics where treatment options can be accessed in one place

#### 4. The role of medical misogyny, underlying gender biases in healthcare and cultural norms that create barriers for women with these conditions

Medical misogyny was an overwhelming theme that ran through the experience of nearly every survey respondent. For women and non-binary people with disabilities, the compounding factors of misogyny and ableism present additional issues with being believed and gaining access to life-changing and life-saving healthcare<sup>910</sup>. This issue is brought to the forefront when discussing diagnosis and treatments for a gendered healthcare issue (endometriosis and chronic pelvic pain).

A majority of survey respondents brought up the fact that their GP did not believe them, understand the severity of their pain, or take action to continue their journey of getting support. Many respondents had to see multiple gynaecologists, GPs or other specialists at different stages of their journey before getting a diagnosis or relevant treatment. The cost of accessing even one professional means that the financial impact of the gendered bias in the medical system is huge for women and non-binary people with disabilities. The trauma of being disbelieved and dismissed in the medical system is not only a barrier for continuing to advocate for treatment for pelvic pain, but also for interacting and trusting anyone in the medical system in the future.

A common experience was to be told that the pain was 'normal' or 'not anything serious' by GPs. Many experienced misdiagnosis by GPs, who did not investigate very far. Some mentioned that they thought their other disabilities impacted how seriously they were taken with regards to their pelvic pain. This experience of diagnostic overshadowing is common for women and non-binary people with disabilities, where the existence of another diagnosis biases a healthcare professional and

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<sup>9</sup> Women with Disabilities ACT (2025). *Submission to the Inquiry into ACT Health System Data, Demand and Processes*. Women with Disabilities ACT. <https://wwdact.org.au/submission-to-the-inquiry-into-act-health-system-data-demand-and-processes/>

<sup>10</sup> Frohmader, C (2019). *The Status of Women and Girls with Disability in Australia*. Position Paper to the Commission on the Status of Women (CSW) Twenty-Fifth Anniversary of The Fourth World Conference on Women and The Beijing Declaration And Platform For Action (1995). DPO Australia and the National Women's Alliances. <https://assets.wwda.org.au/uploads/2020/06/The-Status-of-Women-and-Girls-with-Disability-Asutralia.pdf>

discourages them from investigating co-occurring conditions. This is particularly the case for psychosocial disability.

Some examples of medical misogyny experienced by survey respondents:

- One respondent spent 20 years with pelvic pain and heavy periods, but was never offered support by a GP
- One respondent was offered 'band-aid' solutions by a GP without being taken seriously – including a breast reduction
- One respondent who was over 65 was referred to geriatric services, where one nurse suggested she had dementia

Some respondents were not taken seriously by medical professionals even after commencing treatment, with vital risks and information during the diagnosis and treatment process not disclosed and respondents not able to give informed consent.

### **Respondent recommendations**

There is a significant need for **increased funding to address bias in the healthcare system** which impacts women and non-binary people with disabilities, including funding and incentives for relevant training.

This could include:

- Funding for clinics specialising in women's health and gender-informed care
- Funding for GPs to access training on trauma informed practice
- Funding for GPs to access training on culturally safe practice
- Funding for GPs and medical specialists to access training on disability and neurodivergence, and the risks of diagnostic overshadowing and neglecting to provide holistic models of care
- Funding and incentives to access training on gender diversity in healthcare, to increase the number of clinics offering safe care for non-binary and gender diverse people experiencing chronic pelvic pain

## 5. The economic and social impacts of people in the ACT with these conditions, including education, employment and lost productivity

The experiences of women and non-binary people with disabilities with endometriosis, adenomyosis, PCOS, and other chronic pelvic pain conditions have a significant economic and social impact.

Common themes across nearly all survey responses includes how people had to alter their lives to manage overwhelming and excruciating levels of pain. This included planning day-to-day life around safe access to bathrooms, heat packs and other pain management materials, and safe places or lie down in case of a pain flare.

The impact on workplaces included many respondents being unable to work full time, or needing months of leave from work or university. It was rare to hear of a workplace or employer who was able to accommodate, and respondents faced disbelief and job insecurity, or being unable to access personal/sick leave and needing to accrue annual leave to use to manage pain when unable to work.

The social impact was also large for survey respondents. Some brought up stigma around pelvic pain, impacting relationships with friends and family. Managing high levels of pain also stopped respondents from doing some hobbies, including sports and exercise.

### **Respondent recommendations**

Survey respondents had a few clear recommendations to work towards removing social and economic barriers to accessing diagnosis and treatment. These included:

- Introducing paid menstrual leave and increasing workplace benefits for people with a chronic pelvic pain condition
- Recognise chronic pelvic pain as a disability to increase likelihood of accessing supports such as the Disability Support Pension or appropriate NDIS funding for those who have access

## 6. Education available to medical professionals, allied health professionals, young women and others, on these conditions and treatment options

The respondents to the survey reported a significant need for improving the knowledge of medical professionals, particularly GPs, regarding endometriosis and other pelvic pain conditions.

Many faced a reality of GPs not having the most up to date and current information about presentations, diagnosis and treatment pathways.

As mentioned previously, some experienced that doctors and specialists did not disclose vital risks and information during diagnosis and treatment.

Education around endometriosis and other pelvic pain conditions should work in tandem with education around the risks and impacts of gendered and disability bias in the healthcare system.

Most respondents to the survey were able to find information relevant to them through online information, with some accessing networks of family and friends to find trusted options. An increased level of education for GPs, who are the first point of call in accessing a diagnosis or treatment, would allow people with disabilities to access trusted opinions and have their whole situation taken into consideration.

### **Respondent recommendations**

Aside from **training for medical professionals to improve their knowledge regarding endometriosis and other pelvic pain conditions**, survey respondents suggested there was a **need for improving access to trusted and relevant information** for people experiencing chronic pelvic pain. This could be done through:

- Funding for a centralised ACT Government website page, including educational resources and information, as well as a list of recommended ACT professionals trained in chronic pelvic pain diagnosis and management (including GPs, specialists and allied health professionals)

## Case study

\*Name changed for privacy.

Lisa is an adult living in the ACT in their late 20s who has experienced chronic pelvic pain for 3.5 years following an IUD insertion originally put in for contraception. Initially, their pelvic pain was treated as a direct result of the IUD. Despite Lisa's history of irregular and heavy periods, and family history pointing to an increased likelihood of endometriosis or a related condition, doctors discouraged pursuing this diagnosis because the pain began following an IUD insertion.

Lisa describes the pain as excruciating, often requiring bed rest and lasting several hours. They are unable to work, hang out with friends or leave the house when they are experiencing pelvic pain.

Lisa's experience accessing specialist care has been marked by long delays:

- 4-month wait for their first appointment with a specialist gynaecologist in the ACT.
- 3-month wait for their first diagnostic ultrasound in the ACT (inconclusive)
- 14-month wait for a pelvic physiotherapy appointment through ACT Health. When they were finally seen, the physiotherapist was not qualified to perform an internal exam, limiting the usefulness of the appointment.

Services in Sydney, however, were more accessible:

- An ultrasound at Omni in Sydney was available within one week.

### Quality of Care and Feeling Heard

Lisa reports that while clinicians generally acknowledged their pain, they were dismissive of their other symptoms, their treatment preferences, and their requests for holistic guidance. They describe a pattern of not being listened to, particularly when seeking clarity on next steps or asking for broader support.

Lisa's journey of diagnosis and treatment involved seeing multiple professionals. They described the challenges of managing confusing and conflicting information from different professionals, including directly conflicting information about the safety of different treatment and pain management options. Lisa has self-advocated in seeking clarifying information about their choices, and the risks of various treatment pathways recommended by professionals, and may not have access to the relevant information if they had not self-advocated in this way.

Lisa has struggled to find healthcare professionals who provide holistic care and guidance, taking into account their other conditions and disabilities. They were prescribed a medication which was inappropriate and could have life-threatening side effects because of their co-occurring disabilities. Lisa was not informed of the risks of the medication before it was prescribed, and had taken the medication for multiple weeks before finding out about these risks.

### Navigating Multiple Providers

Lisa has had to consult multiple professionals, including gynaecologists, pelvic physiotherapists, ultrasound providers, and specialised pelvic pain services. They have also had to travel interstate to Sydney for diagnostic imaging and is now considering travelling again to see an endometriosis specialist, as local options are limited.

The overall cost, cumulative wait time and time commitment of accessing these providers is significant (Table 1).

**Table 1: Providers accessed by Lisa and associated costs**

	Cost per appointment (estimate)	Number of different providers per category accessed	Number of sessions accessed in total
GP	\$100 (\$50 back from Medicare)	3-6	10-12
Gynaecologist	\$360	1	1
Ultrasound Provider	\$300 - \$600	3	3

Pelvic Physiotherapist	\$160 - \$210	3	7
Specialist Pain Clinic	\$400	1	1
SHFTPACT Pelvic Pain Clinic	\$0	1	1
Pain psychologist	\$300	1	2
Dietician	\$200	1	4
Osteo	\$200	1	2
Remedial Massage	\$120	1	3

### Financial Barriers

Cost has been a significant barrier throughout Lisa's care journey. In addition to the providers outlined in Table 1, Lisa uses a continuous hormonal contraceptive pill to manage symptoms, but it is not PBS-subsidised, resulting in high ongoing out-of-pocket costs. Additionally, travel to Sydney for specialist services adds further financial strain.

Lisa estimates they spend around \$3000-\$5000 per year on out of pocket expenses related to pelvic pain. They note that without family financial support and full-time employment, they would not be able to afford ongoing care.

### Accessing Treatment and Pain Management

Lisa primarily accesses treatment within the ACT, with one ultrasound appointment in Sydney. They are considering further interstate care due to limited specialist availability locally.

Their ongoing pain management includes:

- Hot water bottle
- Over-the-counter anti-inflammatories (ibuprofen or naproxen every two hours)
- Bed rest

They have repeatedly asked for stronger “as-needed” pain relief but has been told that available options involve daily medications with significant side effects, leaving them without adequate episodic pain management.

### Impact on Daily Life

Chronic pelvic pain significantly disrupts Lisa’s life:

- Before starting continuous contraception, they experienced 2–3 days of debilitating pain each month.
- With treatment, this has reduced to around one day per month, though some months are skipped.
- Pain episodes require them to cancel work, social plans, and hobbies.
- They have used substantial amounts of personal leave, time off in lieu, and annual leave from their workplace to manage pain during flare-ups.

### Mental Health Impacts

Lisa describes a profound mental health toll, including:

- Burnout from constant self-advocacy
- Exhaustion from managing multiple appointments
- Hopelessness and depression due to lack of answers and ongoing pain
- Financial stress related to treatment costs

### Role of Peer Support and Self-Education

Lisa found online forums, friends, and colleagues far more helpful than many clinical interactions. These networks assisted them with:

- Interpreting medical information
- Checking whether advice aligned with current research
- Choosing treatment pathways
- Finding empathetic, informed professionals

They also benefited from:

- Pelvic Pain Australia website
- *Healing Pelvic Pain* by Peta Wright

These resources helped them build their own knowledge in the absence of adequate clinical guidance.

### Disability and Co-existing Conditions

Lisa considers their chronic pelvic pain a disability, alongside other conditions including ADHD and suspected hypermobility. They note emerging research on clusters of conditions affecting AFAB individuals and sees their experience reflected in this pattern.

### Conclusion

Lisa's case highlights the cumulative burden of chronic pelvic pain when healthcare systems lack capacity, coordination, and specialised expertise. Long wait times, high costs, limited treatment options, and inconsistent clinical knowledge have forced them to rely heavily on self-education, peer support, and interstate services. Their experience underscores the need for systemic reform to ensure timely, affordable, and evidence-based care for people with chronic pelvic pain in the ACT.

### **Recommendations**

Lisa's experience of accessing diagnosis, treatment and support is only one case, but their experiences are shared by many who have responded to the survey.

Lisa has suggested the following recommendations based on their lived experience, which have been echoed by other survey respondents:

- More research funding
- Free and longer GP appointments
- Better education for medical and allied health professionals
- Subsidised treatment options
- Paid leave for people experiencing pelvic pain flares
- More specialists and diagnostic tools in the ACT
- Increased capacity for pelvic physiotherapy

- Subsidised laparoscopy surgeries so people don't have to travel interstate
- Investment in new pain relief options
- A centralised ACT Government website with reliable information and a directory of trained professionals

## Conclusion

Across prior research, survey respondents and conversations with members, the significant impact of endometriosis and other conditions causing chronic pelvic pain cannot be understated. Persistent pelvic pain is likely to be experienced by up to a third of women with disabilities in the ACT, and the intersecting barriers of gendered bias in healthcare, ableism and financial barriers result in these conditions having a debilitating impact on quality of life.

WWDACT recommends a range of interventions and funding options to be explored, to ease the financial barriers to treatment, address gendered, disability and cultural bias in the healthcare system, and improve access to diagnosis and treatment options within the ACT. There is work to be done towards removing social and economic barriers to accessing diagnosis and treatment, which if addressed are likely to reduce social stigma around these conditions.

Funding research to increase the evidence base around treatment and pain management, including pain relief medications, and improving access to trusted and relevant information should also be priorities.

Many of the barriers to diagnosis, treatment and pain management would be addressed through the implementation of evidence-based recommendations outlined by Women's Health Matters in their submission to this inquiry. WWDACT re-emphasises our support for their primary recommendation: to develop an integrated, publicly funded pelvic health system in the ACT, covering the full continuum of care from early education and assessment through to specialist and multidisciplinary hospital care, which is free or low cost at the point of access, and supported by a well-resourced network of GPs and community clinicians.

WWDACT supports all recommendations made by Women's Health Matters (WHM). The following WHM recommendations address particular concerns raised by WWDACT's survey respondents, and are likely to make a significant difference to the experience of women and non-binary people with disabilities experiencing chronic pelvic pain:

- Recommendation 5: Expand and make permanent the SHFPACT model of specialised primary care, with 45–60 minute appointments, co-located pelvic health physiotherapy and a dedicated care navigator role.
- Recommendation 6: Fund a second clinic in the north of Canberra to serve the growing Gungahlin and Belconnen populations.
- Recommendation 7: Support and resource the GP network working in this space so that clinicians are equipped, connected and not working in isolation.
- Recommendation 8: Increase investment in established community-based support models to enhance patient care in non-clinical settings, reduce demand on clinical services and improve outcomes for people with pelvic pain conditions.
- Recommendation 9: Invest in building specialist capacity at Canberra Hospital, additional gynaecologists, a properly resourced multidisciplinary team, and dedicated support for clinicians currently operating in an understaffed environment.
- Recommendation 10: Once that foundation is in place, establish a formal Hub and Spoke model linking community clinics across Belconnen, Tuggeranong, Gungahlin and Woden, as well as North Canberra Hospital, to Canberra Hospital as the specialist hub.
- Recommendation 11: Expand the Canberra Hospital Endometriosis Clinic to operate as a true multidisciplinary centre, gynaecology, pain medicine, physiotherapy and psychology as standard embedded components of care, not optional referrals.
- Recommendation 13: Reform the Interstate Patient Travel Assistance Scheme (IPTAS) to reduce administrative burden and better support patients travelling interstate for specialist care unavailable in the ACT.
- Recommendation 14: Work with researchers, Canberra Health Services and private specialists to improve local access to diagnostic and treatment options that are supported by evidence, including consideration of Deep Infiltrating Endometriosis ultrasound and pelvic Botox injections.
- Recommendation 15: Develop skills and knowledge on endometriosis, adenomyosis, PCOS and PPP for GPs,

gynaecologists and emergency medicine physicians, from initial medical training through to continuing professional development.

- Recommendation 16: Establish structured case review and mentoring pathways for ACT-based specialists to build local excision surgery expertise.
- Recommendation 17: Embed trauma-aware and healing-informed care training as a standard component of education for health practitioners.
- Recommendation 18: Establish a formal advanced practice nursing pathway for endopelvic pain within the ACT public health system.
- Recommendation 23: Formalise and fund a care coordination model building on SHFPACT's existing approach, ensuring no patient navigates the system alone.
- Recommendation 26: Continue meaningful engagement with people with lived experience, peer networks and advocacy organisations in health system reform and service development.

WWDACT are happy for this submission to be made public, and to be contacted to provide further information to the Committee about this submission.

For further information please contact [REDACTED] or [REDACTED]

## Summary of respondent recommendations

### **Addressing the cost barrier**

- Increasing the range of treatments subsidised under the PBS or other schemes
- Increased rebates for medical practitioners
- Subsidised longer appointments at GPs

### **Addressing bias in the healthcare system**

- Funding for female friendly clinics
- Funding for GPs to access training on trauma informed practice
- Funding for GPs to access training on culturally safe practice
- Funding for GPs and medical specialists to access training on disability and neurodivergence, and the risks of diagnostic overshadowing and neglecting to provide holistic models of care
- Funding and incentives to access training on gender diversity in healthcare

### **Improving access within the ACT**

- Incentive programs for gynaecologists and other specialists to practice and offer procedures within the public system
- Funding additional specialised pelvic ultrasound clinics, in addition to CFAC in Bruce
- Funding to increase the number of specialists practicing in the ACT
- Funding to improve access to specialist diagnostic tools, such as specialist endometriosis ultrasounds
- Increasing funding and capacity of pelvic physiotherapists within the ACT Health public system
- Provide subsidies for laparoscopy surgeries performed locally in Canberra, for people who cannot afford access through the private system
- Increase number of specialists located centrally in Canberra to improve access to those reliant on public transport
- Pilot multi-disciplinary clinics where treatment options can be accessed in one place

### **Removing social and economic barriers to accessing diagnosis and treatment**

- Introducing paid menstrual leave and increasing workplace benefits for people with a chronic pelvic pain condition
- Recognise chronic pelvic pain as a disability to increase likelihood of accessing supports such as the Disability Support Pension or appropriate NDIS funding for those who have access

**Improving research**

- Funding research to increase the evidence base around treatment and pain management, including pain relief medications

**Improving access to trusted and relevant information**

- Funding for a centralised ACT Government website page, including educational resources and information, as well as a list of recommended ACT professionals trained in chronic pelvic pain diagnosis and management (including GPs, specialists and allied health professionals)