Legislative Assembly for the
Australian Capital Territory
Standing Committee on Social Policy

Submission cover sheet

Inquiry into endometriosis and other pelvic pain conditions

Submission number: 035

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[redacted]

Inquiry into Endometriosis and other pelvic pain

The Committee has resolved to inquire into and report on endometriosis and other pelvic pain conditions, with reference to:

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;**

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;**

3. **the treatment options and supports available in the ACT compared to other jurisdictions, their evidence-based effectiveness and potential side effects and impacts;**

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

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

6. **education available to medical professionals, allied health professionals, young women and others, on these conditions and treatment options;**

7. **research and trials currently being explored in Australia and opportunities for this to take place in the ACT; and**

8. **any other related issue**

Georgia Kate Brady
[redacted]

Access to timely diagnosis and appropriate treatment for endometriosis in the ACT is significantly hindered by a lack of specialised resources. As a result, many patients, including myself, are required to travel interstate to receive adequate care and access specific treatments. Following initial consultations, patients are often referred to multiple additional providers to support diagnosis and management, including pain management specialists, pain psychologists, and pelvic floor physiotherapists. However, access to these services within the ACT is limited, creating further delays and barriers to comprehensive care.

My personal experience reflects these systemic challenges. I began experiencing period-related symptoms at the age of 11, yet it took nearly 14 years to receive a formal diagnosis at 25. Now at 30, I have undergone two laparoscopic surgeries and pursued numerous treatments in an ongoing effort to manage my condition and achieve some level of pain relief. While I have been fortunate to have a supportive General Practitioner who has consistently validated my symptoms, the broader diagnostic journey was long, exhausting, and often dismissive. I was frequently told that I was “too young” or that my pain was simply a normal part of menstruation, responses that contributed to significant delays in diagnosis and treatment.

The impact of endometriosis on my quality of life has been profound. From the age of six, I was deeply involved in dance, continuing this passion into adulthood. However, in 2024, I was forced to give up dancing entirely due to the severity of my symptoms. The pain associated with endometriosis made training, classes, and performing with my team increasingly unmanageable and ultimately unsustainable.

Chronic pelvic pain and ongoing inflammation now affect my daily functioning. To manage this, I rely on strong pain relief, including regular use of opioid medication, simply to complete everyday tasks. I have also had to transition to working full-time from home to better manage my condition and maintain employment in a way that accommodates my health needs.

In addition to barriers in healthcare access, there is a clear gap in education and awareness. Having been born and raised in Canberra and educated locally, including attending an all-girls high school, I never once encountered education around conditions such as endometriosis, adenomyosis, or polycystic ovary syndrome during my schooling. Women’s health issues, particularly those relating to menstrual health, were not meaningfully discussed. This lack of early education contributes to delayed recognition of symptoms, normalisation of severe pain, and ultimately, delayed diagnosis and treatment for many young people.

My experience navigating diagnosis, treatment, and ongoing management of endometriosis in the ACT reflects broader systemic gaps. In addition to my personal journey, I am currently working with Endometriosis Australia to implement the EndoThrive Workplace Accreditation Program within my department, which has further highlighted both the challenges individuals face and the opportunities for meaningful reform.

Georgia Kate Brady
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To address the issues outlined in this submission, I recommend the following:

1. **Improve data collection and visibility (TOR 1)**
   The lack of clear, ACT-specific data on the prevalence of endometriosis and related conditions contributes to these issues being under-prioritised. My own 14-year delay in diagnosis demonstrates how invisible these conditions can remain within the health system. Improved data collection would support more informed policy, funding, and service delivery decisions.
2. **Increase access to local, specialised care (TOR 2 & 3)**
   Like many others in the ACT, I have had to seek care interstate to access specialised treatment. This creates financial, physical, and emotional strain, particularly for those already managing chronic pain. Expanding local access to specialist gynaecologists, multidisciplinary pain clinics, and allied health providers would significantly reduce these barriers.
3. **Establish coordinated, multidisciplinary care pathways (TOR 2 & 3)**
   Throughout my diagnosis and treatment, I have been referred to multiple providers - including pain specialists, psychologists, and physiotherapists - without a clear, coordinated pathway. A more integrated model of care would reduce the burden on patients to navigate complex systems while unwell and improve overall health outcomes.
4. **Address gender bias and medical dismissal (TOR 4)**
   During my teenage years and early adulthood, I was frequently told that my symptoms were “normal” or that I was “too young” for anything more serious. These experiences reflect broader issues of gender bias and the normalisation of women’s pain in healthcare. Mandatory training for healthcare professionals on recognising and addressing these biases is critical to reducing diagnostic delays.
5. **Expand education for healthcare professionals and the community (TOR 6)**
   A lack of awareness among healthcare providers and the broader community contributes to delayed diagnosis and inadequate care. Despite attending an all-girls school in Canberra, I received no education on endometriosis or similar conditions. Increasing education across schools, healthcare settings, and public campaigns would empower earlier recognition and intervention.
6. **Introduce comprehensive menstrual health education in schools (TOR 6)**
   If I had been educated on what constitutes “normal” versus “abnormal” menstrual pain during my schooling, I may have sought help earlier. Embedding this education into school curricula is essential to ensuring future generations are better informed and supported.
7. **Improve access to holistic pain management (TOR 2 & 3)**
   Due to ongoing chronic pelvic pain and inflammation, I now rely on strong pain relief, including opioids, to manage daily life. Greater access to multidisciplinary pain management

options - including physiotherapy and psychological support - would reduce reliance on medication and improve quality of life for many patients.

8. **Recognise the economic and social impacts (TOR 5)**
   Endometriosis has significantly impacted my ability to participate fully in both work and personal life. I was forced to give up dancing - a lifelong passion - due to pain, and I have had to transition to full-time remote work to manage my condition. Through my involvement in the EndoThrive Workplace Accreditation Program, I have seen firsthand how workplace awareness and flexibility can support individuals to remain engaged in employment. Expanding such initiatives across the ACT would help address lost productivity and improve wellbeing.

9. **Support research and innovation in the ACT (TOR 7)**
   Increased investment in research and clinical trials within the ACT would improve access to emerging treatments and contribute to better long-term outcomes. Given the complexity and variability of endometriosis, continued research is essential.

Closing Statement

My experience is not unique. It reflects a broader pattern of delayed diagnosis, limited access to care, and the normalisation of significant pain. However, through initiatives such as the EndoThrive Workplace Accreditation Program and increased awareness, there is a clear opportunity to improve outcomes for those living with endometriosis and other chronic pelvic pain conditions in the ACT.

Without meaningful reform, individuals will continue to face avoidable delays, ongoing pain, and barriers to fully participating in education, employment, and daily life.