INQUIRY INTO ENDOMETRIOSIS AND OTHER PELVIC PAIN CONDITIONS

SUBMISSION TO THE LEGISLATIVE ASSEMBLY FOR THE AUSTRALIAN CAPITAL TERRITORY STANDING COMMITTEE ON SOCIAL POLICY

WHAT IS THIS SUBMISSION ABOUT?

- This submission responds to the Inquiry Terms of Reference about endometriosis, adenomyosis, PCOS (polycystic ovary syndrome), and chronic pelvic pain in the Australian Capital Territory. These conditions cause persistent pain and other symptoms that significantly impact people's lives.

HOW COMMON ARE THESE CONDITIONS?

- Endometriosis affects about 1 in 7 women and people assigned female at birth
- In the ACT, about 19% of survey respondents reported having endometriosis or adenomyosis
- PCOS affects roughly 1 in 7 people (around 14%)
- About 17% of people experience persistent pelvic pain lasting six months or more

- These numbers are likely underestimates because many people go undiagnosed.

- ***The main problem: Diagnostic delay***

- It takes 7-12 years on average for people to get diagnosed after their symptoms start. This happens because:
    - Symptoms are dismissed as "just bad periods"
    - Pain is often not taken seriously in healthcare
    - There are long waiting lists for specialist appointments (6-12+ months in the ACT)
    - Some people face additional barriers based on their identity or circumstances

WHO IS MOST AFFECTED BY DELAYS?

- Delays and poor care are worse for:
    - Aboriginal and Torres Strait Islander peoples who face racism and culturally unsafe healthcare
    - People from culturally diverse backgrounds who encounter language barriers and cultural misunderstandings
    - Gender-diverse and transgender people who face services designed only for cisgender women
    - People living in larger bodies whose symptoms are wrongly blamed on their weight
    - People with disabilities whose pain is mistakenly attributed to their existing conditions
    - Young people and those with lower incomes who can't afford private healthcare

WHY DOES THIS MATTER?

- These conditions affect every part of life:
    - Education: Missing school or university due to pain
    - Work: Taking sick leave, reduced productivity, job insecurity
    - Mental health: Depression and anxiety from chronic pain and being dismissed
    - Social life: Difficulty participating in activities
    - Money: Lost income, high medical costs, reduced career progression

WHAT NEEDS TO CHANGE?

- The submission recommends the ACT Government:
    - Reduce waiting times for diagnosis and treatment
    - Create culturally safe services designed with Aboriginal, CALD, LGBTIQ+, and disability communities
    - Make care more affordable by subsidising allied health services like physiotherapy and psychology
    - Train healthcare workers to recognize symptoms early and provide respectful, unbiased care
    - Improve education for young people about what's normal and what's not
    - Support people at work and school with flexible arrangements
    - Invest in research to improve diagnosis and treatment
    - Collect better data to understand who is being left behind

THE BOTTOM LINE

- These conditions are real, common, and serious. They're not "just bad periods" or "all in your head."
- Current delays and barriers are not inevitable, they're the result of system design that can be changed.
- Not everyone experiences the same barriers. People facing multiple disadvantages wait longest and suffer most. Any reforms must center those who've been most left behind.
- The ACT has a genuine opportunity to lead. With intentional, equity-focused investment, the Territory can show Australia what good pelvic pain care looks like.

THE BIGGER PICTURE

- These aren't just medical issues - they're about fairness and equality. Right now, people with money and privilege get diagnosed and treated faster, while those facing disadvantage wait longer and suffer more.
- The ACT has an opportunity to lead Australia by:
  - Designing services that work for everyone, especially those currently most disadvantaged
  - Making sure care is not just available, but actually accessible and respectful
  - Recognizing that reducing diagnostic delay and improving care is both a health issue and a social justice issue

WHAT DOES THIS MEAN FOR YOU?

- If you or someone you know experiences:
  - Severe period pain
  - Pain during sex
  - Heavy or irregular periods
  - Persistent pelvic pain
  - Difficulty getting pregnant

- *This is not normal, and you deserve investigation and support*. These symptoms should be taken seriously, regardless of your age, background, body size, or any other factor.

KEY TAKEAWAY

- Endometriosis, adenomyosis, PCOS, and chronic pelvic pain are common, serious, and often dismissed. The ACT can do better by ensuring everyone, especially those currently facing the greatest barriers, can access timely, respectful, effective care.

WANT TO KNOW MORE?

Full submission available at: Committee website

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For support and information:

- Endometriosis Australia: endometriosisaustralia.org
- Women's Health Matters ACT: womenshealthmatters.org.au
- Pelvic Pain Foundation of Australia: pelvicpain.org.au