



Submission cover sheet

Inquiry into endometriosis and other pelvic pain conditions

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Legislative Assembly for the Australian Capital Territory

Standing Committee on Social Policy

Parliamentary Inquiry into endometriosis and other pelvic pain conditions.

Dear Committee,

I write this submission as the parent of an 18-year-old who is currently trying to recover from her first Endometriosis laparoscopy which took place three weeks ago.

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.

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

The pathway to diagnosis has taken 8 years, despite her symptoms of nausea, bowel problems and heavy, painful periods being reported to numerous General Practitioners, Paediatricians and Gastroenterologists during this entire time. Trying sensible at-home remedies, medications, ultrasounds, finding paediatric gastroenterologists (then not easily accessible in Canberra), undertaking endoscopies twice, and then undergoing a colonoscopy was challenging and very expensive, only to eventually receive a diagnosis of Irritable Bowel Syndrome and Chronic Gastritis in April 2024. When finally referred to a private Gynecologist (due to the wait time in the public system) in October 2024, she was able to identify that in addition to the heavy painful periods, my daughter's significant digestive problems were actually a symptom of Endometriosis. This was proven correct at the recent Endometriosis laparoscopy, where my daughter needed a number of separations of scar tissue adhesions, including the sigmoid colon

and her abdomen, and 10cm of her colon, due to endometriosis. It seems that endoscopies and colonoscopies can diagnose only what is seen inside the digestive system, not the pathology impacting it which is occurring directly on the outside of the digestive system. Whilst our paediatricians and gastroenterologists were very knowledgeable and we had great faith in them and their experience, I can only wonder whether training and awareness of Endometriosis and its associated symptoms and possible presentations is low, as Endometriosis was not suggested as an area to investigate for further referral. I felt I had to push very assertively for a gynecologist referral via a GP after ruling everything else out and performing my own personal research. Once we saw the gynecologist, which took a number of months following the initial referral, the gynecologist stated that it was very common for Endometriosis patients to undergo testing for irritable bowel symptoms as Endometriosis can cause these symptoms. Therefore, my daughter is not the only case where this has happened. This lack of Endometriosis presentation awareness in other specialties meant that several years were added to extending the time for diagnosis, in addition to her undergoing additional procedures and anesthetics at young ages, with significant financial expense and time off school and work to attend multiple medical appointments.

Aware that people through the public system are reporting waits of up to three years to have a laparoscopy, I felt we had no choice but to have her laparoscopy conducted privately. As a single parent, with already high medical expenses and the challenges of today's economy, it is an awful position to be placed in, knowing that your daughter's day-to-day wellbeing and future fertility, health, educational, and employment needs require immediate response, not risking her future by waiting for an additional three years to the eight years that it has already taken for diagnosis. This is also taking place at a time in her life where she is trying to undertake studies and establish her future career. Pain management access has been via medication, which my daughter found caused terrible headaches or exacerbated her digestive problems to the point she could not attend College.

Careful planning occurred around her Year 12 studies timetable and she has taken a gap year this year in order to have a laparoscopy, to minimize disruption to future university studies and allow her to even be in the position to be healthy enough to properly participate in higher education. Waiting on the public system would add not only significant risk to her health, but also increase uncertainty and stress around how her future studies could occur. I felt I had no choice but to proceed with private laparoscopy, which cost \$7,715 and has placed me in a very negative financial position. The stress this has caused is immense. It has very much made me feel like I am trying to access medical care in the USA, not Canberra, Australia.

I additionally wish to mention that last year she suffered from four episodes of tonsillitis during Year 12, these episodes lasted for weeks on end, despite prompt intervention with long courses of antibiotics which would not work, to the point she became dehydrated with elevated heartrate and ended up on intravenous antibiotics in The Canberra Hospital. She had only ever had tonsilitis once in her life previously to last year. The gynecologist has explained that this condition can be related to Endometriosis, as Endometriosis causes elevated inflammation and disturbs immune cell function, so women with Endometriosis experience poorer ability to fight off infections and worse symptoms during infection. My daughter's GP who was alarmed at how ill she was and how much the tonsillitis was affecting weeks of her life, and stopping her ability to undertake major Year 12 assessment, strongly recommended she have a tonsillectomy and referred her to The Canberra Hospital, where she had previously been given the IV antibiotics and they noted how ill she was and were concerned about the risk of possible sepsis. The Canberra Hospital rejected the referral. With needing to finance the laparoscopy, I have been unable to pursue a private tonsillectomy, so this has not been able to happen despite her doctor's recommendation. Again, accessing health care is becoming more and more unreachable and impossible to get, when the long-term costs to a young person of not receiving timely and reasonable medical care are even more significant, this does not make economic sense. Perhaps more training and education need to be provided to medical professionals across hospitals such as The Canberra Hospital, so that these patients can be triaged and receive some medical care at all.

Lastly, I have found the general community is not well informed about Endometriosis, about how serious it is and how severe the pain can be. This has meant that accessing personal support or understanding can be at minimal levels, which makes managing a chronic disease even harder, and incorrect advice is given. People will say, 'oh just need to get a hysterectomy' even though this is not a cure, or believe that having a baby will fix it, as one GP once told my 17-year-old daughter. Further education (particularly targeting older adults) would be beneficial.

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

I have already spoken about the economic costs as the parent for medical appointments and medical procedures, which does not take into account numerous medications (such as 12 months on Slynda when it was nearly \$100 a script and no PBS), and time off work over the

years to provide support. I would dearly like to reduce my private health insurance coverage due to cost, but fear that this is not possible with my daughter's condition and future treatment requirements.

For my daughter, she has experienced daily digestive symptoms and pain, and heavy periods that mean leaving the house can be extremely difficult. These have greatly disrupted her school attendance through primary school, high school and college, significantly impacting her academic results, social functioning and confidence. The education system has been extremely unhelpful. Despite COVID showing that hybrid online learning can occur, teachers would not let her attend any classes virtually. Accessing class materials has usually been extremely limited, and with no access to classroom discussions or teacher guidance through any resources, her education has been extremely affected as a result. It is very difficult to remain motivated in the face of this and she has had times of being very overwhelmed with needing to undertake large amounts of work to submit in short time frames, with no teacher assistance, which her peers had many more days to complete, under the guidance of their teachers in-class, to achieve higher grades. It was due to the School Recommendation Scheme that she was able to get university entry. I am not sure why her College did not inform her of this Scheme, it was only that I was aware of it that enabled her to try and access this application process. I feel more awareness of these schemes could be created so that students with disability and medical conditions could access the very schemes designed to help them access future education opportunities.

Endometriosis has also impaired my daughter's ability to participate in work. It is not a condition that allows reliability or one to be able to function normally, and just being able to try and keep up academically has been enough of a challenge with her health. These effects have been devastating to witness, where a person with numerous talents and positive desire to participate in her school community, sports, work and the arts, has had these experiences roughly taken from her. Whilst her College drama teacher said to me that she was the best actress in the class, and the best script reader she had ever seen in over 20 years, that teacher would not cast her in a role in the class drama productions "in case she was not able to attend on the night", even though historically she had always pushed through the pain to not miss performances. Instead of participating in this group assessment, she would have to do her own private project, which isolated her further. The stigma of having a medical condition that requires management, means that discrimination occurs to prevent patients being able to participate even when they can. As a result, my daughter has completely eschewed her passion for drama and turned her back on what she once wished to pursue as a career. This also

occurred in other subjects- the message was that you have a medical condition so you could let the group down, when the reality was that when she was in a group project, she was the one leading and carrying the group work, contributing meaningfully and doing the work others couldn't do. It is a devastating message to receive that the teaching staff believe you cannot make a valuable contribution, at a time when one is already feeling vulnerable.

Currently she is hoping to find a casual job once she has recovered from her laparoscopy, as she is still experiencing cramping and heavy bleeding. She has placed numerous job applications with zero responses. Instead of this clever, talented 18-year-old, feeling like the world is her oyster, she is being shut out. I have to completely financially support her, which, at a time when she wants to develop her independence, causes her more distress. I don't believe that at her age she is able to access any government financial support.

We can only cross our fingers and hope that her Endometriosis will be improved after this laparoscopy so that she can participate equally and to her full potential at university next year. She has already been told at this point by her gynecologist that she will need more surgery in five years' time and probably every five years. Can her life and professional career be organized around these timeframes? Can we afford to pay for all these procedures? I am also aware that many patients require more frequent surgery in shorter timeframes, and as a parent I worry about the economic impact on her life and her ability to find an understanding workplace. In the meantime, I truly hope medical research can develop more choice around Endometriosis management, and hopefully one day develop a cure, so these women can have the freedom to live their lives and contribute to society without having the shackles of Endometriosis holding them back like they are.