



THRIVE
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Submission to the SA Parliamentary Select Committee on Endometriosis

Dr. Alecia Macrow BMBS FRACGP Thrive Family Practice

Introduction

As a General Practitioner with a special interest in endometriosis and pelvic pain management, I have seen firsthand the transformative impact of holistic, transdisciplinary, woman-centred care.

Thrive Family Practice, one of twenty-two clinics nationwide awarded a 2023 grant to enhance care for endometriosis and persistent pelvic pain, has treated hundreds of women suffering from significant pelvic pain. Many of these patients have endured years of struggle within the health system, often without finding relief and sometimes even experiencing worsening symptoms.

Our program focuses on respecting women and their autonomy, listening to their stories, recognising pelvic pain as an identifiable syndrome, and developing personalised management plans. We emphasize excellent inter-practitioner communication and comprehensive education, always considering the patient's goals and preferences.

I fully support the submission from my colleagues in the Adelaide Pelvic Pain Network and wish to add my own experiences and perspectives from our Pelvic Pain-focussed clinic. This submission aims to highlight the importance of shifting from a narrow focus on the microscopic aspects of endometriosis to a broader, holistic approach to pelvic pain management.

I express my gratitude to three of our patients who have generously shared their experiences, included at the end of this paper with their consent. I will reference these stories to illustrate my observations.

Recognizing and Treating Pelvic Pain

In General Practice, the real challenge often lies in the questions we ask.

All too often, discussions about pelvic pain become bogged down with the question of whether endometriosis may be present. The more crucial question should be: does this person have pelvic pain, and how can we manage it comprehensively?

Focusing on diagnostic uncertainties leads to unnecessary delays in identifying and treating women with pelvic pain, which ultimately harms patients, burdens the health system, and impacts the broader community.

The Inter-relatedness of Persistent Pelvic Pain

Pelvic pain, when left untreated, usually involves pelvic floor dysfunction. The increased muscle tone and pain in the pelvic floor can cause a knock-on effect which can lead to pain and dysfunction in the bladder, bowel, and vulva, as well as causing pain in the back, hips, vagina, rectum, and thighs.

This cascade of symptoms is not just a local phenomenon occurring in the pelvis but is influenced by a bidirectional relationship between the body and mind. The framework we use to understand and also explain this complex phenomenon is what we call the 'NEI ensemble' (Thacker et al, 2013).

The Drivers of Pelvic Pain

Endometriosis can drive pelvic pain, but it can also have other triggering factors or a combination of factors. These include:

- **Adenomyosis:** A condition where the inner lining of the uterus breaks through the muscle wall of the uterus.
- **Sexual Trauma:** Past experiences of sexual violence can lead to chronic pelvic pain.
- **Recurrent UTIs:** Frequent urinary tract infections can sensitize the pelvic nerves.
- **Pelvic Infection/Pelvic Inflammatory Disease:** Infections in the reproductive organs can cause lasting pain.
- **Surgical Trauma:** Previous surgeries in the pelvic area can lead to adhesions and chronic pain.
- **Trauma and Abuse:** A history of physical or emotional abuse can predispose individuals to chronic pain conditions.

Critically, it is important to recognise that a diagnosis of endometriosis is not required to identify and start to manage pelvic pain. Adequate management of pelvic pain through the below approach will improve symptoms and halt the progression of underlying pathology, including endometriosis. In her story, C notes her fears about what we might do if endometriosis was not found at laparoscopy, which is a fear that I hear expressed often. It was exceptionally helpful for her to understand that the presence of endometriosis at laparoscopy is not essential to understanding and treating someone's pelvic pain.

Our experience at Thrive has shown that early recognition and appropriate management of pelvic pain can significantly reduce the distress and impact on patients' lives. Our team-based, GP-led approach involves:

- Ruling out and/or treating important mimics such as coeliac disease, pelvic infections, inflammatory bowel disease, and malignancy.
- Suppressing periods through hormonal treatments, which is an effective element of treatment for endometriosis, adenomyosis, and other types of persistent pelvic pain
- Managing bowel dysfunction with dietary review, supplements, medications and physiotherapy (a simple daily fibre supplement can be a game changer).
- Addressing pelvic floor dysfunction with education, physiotherapy, simple pain management and appropriate exercise and stretching advice.
- Providing psychological support to address the emotional and social aspects of chronic pain.
- Comprehensive education to help women understand their condition and give them back their agency.
- Involving a transdisciplinary team as required, including referring to appropriate non-GP specialists (eg gastroenterology, gynaecology) if care needs are complex or the patient is not improving with the above techniques.

The NEI Ensemble

To understand pelvic pain fully, we find it helpful to consider a framework such as the 'NEI ensemble' – representing the complex interplay of the nervous, endocrine, and immune systems. The NEI ensemble plays a crucial role in how we experience pain, particularly chronic pain such as that seen in endometriosis and pelvic pain syndromes.

Looking at pelvic pain through the lens of a framework such as the NEI ensemble can help us understand the involvement of other symptoms associated with pelvic pain. Many of the women we see with pelvic pain are also impacted by headache, fatigue, low mood, nausea, vomiting, anxiety and depression.

To further explain the involvement of these interconnecting systems:

Neurological System: The nervous system includes the brain and spinal cord (central nervous system) and the peripheral nerves. Pain signals from the pelvis are transmitted through these nerves to the brain, where they are processed and interpreted. In conditions like endometriosis, these nerves can become hypersensitized, leading to heightened pain perception. Increased sensitivity and activation of the 'fight-flight system' can trigger activation of inflammation and the release of stress hormones.

Endocrine System: The endocrine system, which includes glands that secrete hormones, regulates many bodily functions. Hormonal fluctuations, such as those associated with menstrual cycles, can exacerbate pain symptoms. Stress hormones like cortisol can further influence pain perception and inflammatory responses. Increased circulating levels of stress hormones can trigger inflammation, and also upregulate the 'fight-flight' part of the nervous system.

Immune System: The immune system responds to injury or infection with inflammation, a key contributor to pain. Chronic inflammation, as seen in endometriosis, leads to ongoing tissue damage and pain. The immune response can perpetuate the pain cycle through the release of

cytokines and other inflammatory mediators. As per the above, an increase in inflammation can trigger an increase in the sensitivity of the nervous system as well as the release of more stress hormones.

The NEI ensemble is sensitive to the context of a person's life. Factors such as a history of trauma, abuse, neglect, domestic violence, and unstable income can sensitize individuals to pelvic pain. Additionally, the experience of pelvic pain itself—including not being listened to, not getting answers, ineffective treatment, medical trauma, and the financial burden of treatment—can increase stress, which further activates the NEI ensemble and exacerbates pain. This creates a feedback loop where pain leads to stress which in turn leads to more pain.

The Endo and Pelvic Pain and Impact Tangle

Our life-sized "Pain Tangle" model explores this interconnected system, and we would be pleased to present it to the Committee to explain these concepts further. The pain tangle is a visual representation of the various factors and systems that interact and contribute to the experience of chronic pelvic pain. It highlights how intertwined the physical, emotional, and social aspects of pain are, and how addressing these comprehensively can lead to better outcomes.

Understanding and acknowledging patients' pain experiences is essential for effective pain management (Quintner, 2016).

In our experience, there can be no progress until the patient's experience has been fully validated. Please refer to all three of our patient stories for their reflections on the importance of having their pain understood, validated and acknowledged.

Endo Action Plan

We have developed an 'Endo Action Plan' based on the asthma action plan model. This plan focuses on 'preventers,' such as menstrual suppression and techniques to relax the pelvic floor, and 'relievers,' like regular simple analgesia for flare-ups. This structured approach has empowered many of our patients to take control of their condition and manage their symptoms more effectively.

Studies have demonstrated that asthma action plans significantly improve asthma control, reduce symptoms, and decrease hospital admissions. For instance, a Cochrane systematic review found that personalized asthma action plans led to fewer hospital visits and enhanced patient confidence in managing their condition (Gatheral et al, 2017). Additionally, self-management interventions, including written action plans, were associated with fewer hospital admissions and better health-related quality of life for asthma patients (Foster et al, 2017). Just as asthma action plans have been shown to reduce flares, severe disease, and hospitalizations, our Endo Action Plan aims to provide similar benefits by equipping patients with the knowledge and tools they need to proactively manage their endometriosis.

Endo First Aid Shared Medical Appointments

Our Endo First Aid groups and Shared Medical Appointments (SMAs) that are facilitated by myself and Exercise Physiologist Cherie Noble. These workshops are semi-structured and allow space for members to listen and learn from one another as well as provide a safe environment with more time to explore issues with the facilitating health professionals.

Feedback from participants has been overwhelmingly positive:

- "Absolutely loved it! And it was nice to meet everyone and validating just knowing that what felt like years of going through something alone, others are going through the same." - Patient Ay
- "Was super validating too." - Patient T
- "I'm feeling empowered knowing that there's so many options out there and the support and inclusivity of the whole group yesterday was so reassuring." – Patient An

These sessions cover a range of topics, including understanding the anatomy and physiology of pelvic pain and the NEI ensemble, pain management techniques, movement, stretching and breathing exercises, and coping strategies. The interactive nature of the groups allows participants to share their experiences and learn from one another, fostering a sense of community and mutual support.

Research has shown that shared medical appointments can lead to significant improvements in clinical and behavioural outcomes for chronic conditions. SMAs are effective in enhancing patient satisfaction, improving health outcomes, and reducing the demand on healthcare services (Egger et al, 2013). These findings support the benefits of our Endo First Aid groups in providing comprehensive and effective care for individuals managing pelvic pain.

Please refer to the comments in all three of our patient's stories for their perspective on the Endo First Aid program.

Use of Specialist Nurses

Our endo and pelvic pain trained nurses work closely with patients as part of our GP-led team. They are an important touch point for patients, removing some of the common barriers to timely and effective care. They:

- Lead the care planning role, working collaboratively with the patient.
- Are skilled at providing patient education.
- Provide support via email, allowing patients to have their concerns addressed quickly and usually without out-of-pocket costs.
- Liaise with team members as required, ensuring coordinated care and reducing the need for unnecessary appointments (see B's story).
- Fast-track appointments with the appropriate practitioner (see Tash's story).
- Follow-up with patients after case conferences to keep them informed.

Building an Appropriate Care Team

Effective management of pelvic pain requires a team-based approach. At Thrive, we have built a comprehensive care team that includes:

- GPs Dr Alecia Macrow, Dr Kylie Booth, Dr Elaine Leung, Dr Georgie Minns
- Specially trained Registered Nurses Adlyn Melvin and Nicole Barrett
- Titled pelvic floor physiotherapists Carolyn Berry and Alycia Scannell
- Exercise physiologist Cherie Noble
- Dietitian Nicole Moore
- Psychologists – individually chosen per patient needs
- Gastroenterologist – Dr Paul Spizzo

- Gynaecologists – Dr Tran Nguyen and Dr Preetam Ganu
- Pharmacist – Richard Thorpe

In our practice, we use the term "transdisciplinary" rather than "interdisciplinary" to emphasize our integrated approach to patient care. "Transdisciplinary" means that our healthcare professionals collaborate seamlessly, blending their expertise to create comprehensive, holistic treatment plans. This approach ensures that care is not just multi-faceted but truly unified and patient-centred, leading to more effective and cohesive outcomes.

Our group meets regularly to discuss cases (with consent), develop customized treatment plans, share knowledge, and support one another.

Of course, we are keen and happy to work with other practitioners with whom a patient has an existing relationship, especially their own GP if they have one, existing allied health practitioners and non-GP specialists.

Drawing from our patient stories to illustrate the benefits of a new approach

B's Story

B's journey through the healthcare system exemplifies the frequent failure to recognize and treat the broader symptoms of pelvic pain, including pelvic floor and bowel symptoms. Before coming to Thrive, B experienced a fragmented approach to her care, bouncing between various specialists without a coordinated plan, and notes times where she was referred to practitioners without the needed experience or expertise. At Thrive, she benefited from working with a GP who had a strong transdisciplinary network, where each practitioner understood each other's work and scope of practice. A case conference was held to ensure all practitioners and B were on the same page, which reduced fragmentation and unnecessary appointments and costs. Additionally, B found significant value in our Endo First Aid program, which provided comprehensive education and practical strategies for managing her condition.

C's Story

C's experience highlights the inefficiencies of the current care system. C noted fragmentation of care through being referred to several different non-GP specialists without communication or coordination, as well as having a number of repeated ultrasounds and tests. She also notes frequent Emergency Department presentations due to pain exacerbations and the associated fear of severe disease and harm. She had been dealing with intense bowel symptoms related to her pelvic pain, leading to frequent work absences and social withdrawal. At Thrive, we provided her with a tailored treatment plan involving dietary change, pelvic floor physiotherapy, and regular follow-up consultations. This comprehensive care allowed C to manage her symptoms effectively, as well as allowing her to reduce and cease powerful pain and sleep medications while also no longer needing to present to Emergency.

Tash's Story

Tash suffered from persistent and recurrent pelvic pain, which significantly affected her daily life and mental health. She similarly reports ambulance calls, hospital trips and powerful opioid medications. At Thrive, her condition was correctly identified as part of a broader pelvic pain syndrome. She was provided with a personalized treatment plan, incorporating physical therapy, pain management, and psychological support.

Tash's experience of presenting to Emergency also alludes to the benefit of our model of care as an alternative. From hospital, Tash was able to email one of our specialist nurses who was able to liaise with me, and we were able to fit her in to see me on the same day. As there was already a therapeutic relationship, I could see there was a problem with Tash from the waiting room, as I could see Tash looked pale and unwell. On examination she had her Mirena device stuck in her cervix (activating her nervous system, making her look and feel awful). I was able to remove and then put in place a plan to replace this when it suited her.

Key Recommendations for Improved Care

1. Better Collaboration Between Primary Care and Public Hospital Outpatients:

According to SA Health's published outpatient waiting time information, our local hospital Flinders Medical Centre currently has a median wait time of 10 months for gynaecology services, with a maximum wait time of 44 months. Many of the patients waiting the longest will have been referred for pelvic pain. Many of those with pelvic pain on wait lists will not have had access to the type of simple and cost-effective but comprehensive health care that a practice such as ours can offer and would likely have some immediate benefits, as evidenced by the patient stories. Some patients could likely come off the waiting list altogether. Importantly, shortening wait lists would mean that higher priority patients who really need complex tertiary care and/or access to public elective surgery/laparoscopy could be seen sooner.

It would be great to develop a system where Hospital Outpatient referrals can be evaluated and patients offered a comprehensive GP led team approach to care to get underway while they are waiting. We understand this model is being trialled by one of the other 'Endo 22' Clinics in Canberra. We would be happy to contribute to the development of a shared model of care between public hospital outpatients and a clinic such as ours.

2. Increased Recognition of the Role of Quality General Practice in Effective Care:

The profession of General Practice has faced significant challenges over the past 15 years, resulting in a detrimental impact on its capacity to provide comprehensive care. Minimal investment and a prolonged freeze on Medicare rebates have imposed a financial pressure that favours shorter, reactive consultations. This financial strain has led to a decline in General Practice as a specialty, driving many professionals to other fields and deterring new medical graduates from entering GP training. GPs can lead excellent, coordinated, individualized, and effective care when appropriately resourced to do so, as we have been able to demonstrate in a very short time with a Federal Grant. Poor investment in primary care leads to poorer outcomes and greater (and more expensive) need for secondary and tertiary care, surgeries, ambulances being called, ramping, ED presentations, hospitalizations and prolonged outpatient waiting times.

3. Investment in Transdisciplinary Care:

There is little incentive in the current healthcare system for practitioners from different fields to work together collaboratively and in creative ways. Many patients note that they have bounced around different specialties 'like a pinball,' often being referred to or, like B, seeing practitioners without the correct expertise, or several different practitioners

not joining the dots between concurrent issues (such is in C's story). Our practice has done this as a part of the development of our model of care, however, increasing access to funding for transdisciplinary care—such as shared medical appointments and multi-D team meetings—would be an excellent investment. Expansion of the EPC program, allowing higher rebates and more visits for allied health seeing patients under a GP care plan would reduce disease burden and reliance on the public hospital system.

4. Recognizing the Importance of Training and Employing Specialist Nurses:

Specialist nurses, operating within a comprehensive, GP-led team can play a critical role in managing complex conditions like endometriosis and pelvic pain. At Thrive Family Practice, our nurses offer individualized support, helping patients find effective solutions and navigate their care journey. This role includes regular follow-ups, motivational interviewing to explore sustainable lifestyle change, and personalized plans that empower patients to take an active role in their health management. Proper funding and recognition of specialist nurses, working within a GP-led team can lead to better patient outcomes, reduce the burden on other healthcare providers, and improve the overall efficiency of the healthcare system. Supporting the training and employment of these nurses is an investment in quality care, patient empowerment, and a more sustainable healthcare system.

5. Increased Funding for GP-Based Research:

Funding to evaluate effective GP-led care models, would not only enhance patient care but also contribute valuable data to the broader medical community, helping to refine and improve treatment protocols for endometriosis and pelvic pain.

6. Funding Practitioner Training:

Many health practitioners would benefit from training to allow them to identify pelvic pain and help direct women towards appropriate channels. GPs are already skilled in providing complex care, and it would not require a huge investment to upskill GPs and others to recognise and treat the predictable pattern in pelvic pain syndrome. This training would foster a more informed and capable healthcare workforce, ultimately leading to better patient outcomes and more efficient use of healthcare resources.

Conclusion

The journey of understanding and effectively managing pelvic pain, including endometriosis, requires a comprehensive and compassionate approach. At Thrive Family Practice, our experiences have shown that early recognition, quality patient education, holistic treatment, and transdisciplinary collaboration can make a significant difference in the lives of those affected by chronic pelvic pain. By focusing on the broader symptoms and the interconnected nature of the nervous, endocrine, and immune systems, we can provide care that not only addresses the physical aspects of pain but also supports the emotional and psychological well-being of our patients.

The stories of B, C, and Tash illustrate the profound impact that a well-coordinated, patient-centred approach can have. Their experiences highlight the importance of a supportive general practice, transdisciplinary care, and the critical role of specialist nurses in managing complex

conditions. These patient narratives underscore the need for systemic changes to enhance the quality of care and improve outcomes for those suffering from pelvic pain and endometriosis.

Our recommendations aim to address these systemic issues by advocating for increased recognition of the role of general practice, investment in transdisciplinary care, funding for specialist nurse training, better collaboration between primary care and public hospital outpatients, and increased funding for GP-based research and practitioner training. These changes will not only improve patient outcomes but also reduce the overall burden on the healthcare system by decreasing the need for secondary and tertiary care, emergency department visits, ramping, hospital outpatient waiting times and hospitalisations.

A shift towards a more holistic, integrated, and well-supported healthcare model is essential for effectively managing endometriosis and pelvic pain. By investing in these areas, we can ensure that patients receive the comprehensive care they need, leading to better health outcomes and an improved quality of life. We are committed to continuing our work in this field and look forward to contributing our expertise to further enhance care for those affected by these challenging conditions.

Kind regards



Dr Alecia Macrow
GP and Director
Thrive Family Practice
88-90 Partridge St
Glenelg South SA 5045
T 8490 7810

References

B's Story. [Reference from B's story document provided]

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Tash's Story. [Reference from Seven Years - Endo Letter document provided]

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B's Story

B is a self employed lady in her 40s with a young family

I wanted to take a quick moment to fully appreciate and commend Thrive Clinic and especially Dr Alecia for the **care centred** experience that I have received since attending the Thrive Clinic.

My Endometriosis journey began when I was 14 and has been hard, painful, expensive and long. I came across Thrive Clinic after seeing a very lucky socials post and called the clinic straight away. I had been chasing a referral to a gyn for over a year without luck and was desperate to talk to a Dr or specialist with current Endo knowledge about my persistent symptoms. I had been discussing my symptoms with current GPs for almost **5 years** with no progress to show for it.

Within **6 weeks** of seeing Dr Alecia I was already on a journey of improved health, current symptoms reviewed and a Care Plan in place for Endo management. I was in fact blown away by how quickly Alecia was able to diagnose my current state of health and move forward with treatment, a true testament to her and the way the Thrive Clinic is able to support women with Endometriosis through their team of health care professionals. It is what I have been struggling to achieve with GPs who are not educated in Endo, who are not interested in updating their knowledge of Endo, who do not have the understanding to pick out Endo related symptoms and do not have a network of health practitioners that are experienced in this area. It's often felt like 'guess work', sent off to this practitioner or that hoping they might be able to help. Something I can't afford and don't have time for.

I am so incredibly grateful for the exceptional health care service that Thrive is providing. I have found it to be targeted, current, holistic and comprehensive. Since attending Thrive I have had all current symptoms reviewed through an extended initial consultation appt. It was here that Dr Alecia quickly pinpointed symptoms that needed to be addressed straight away. These were symptoms that I had raised with my current GPs on multiple occasions and no action was taken, the severity misunderstood or I was sent to practitioners with no experience of patients with Endo and this lack of knowledge actually made my symptoms worse or left them untreated. Alecia then took my case to a Case Conference of practitioners and specialists to work through and prioritise the other symptoms and which practitioners I should see next to address my symptoms. Again, this process was targeted and helped to save time and money for myself and eliminated the painful and time-consuming nature of referrals to specialists or health care providers, instead allowing me to move on with targeted treatment sooner.

When I first saw Alecia I was feeling overwhelmed and rather desperate and hopeless with my current condition and felt really stressed and concerned for the state of my health and worried for my future. I was worried that my condition might not improve or that there may have been a different reason for always feeling so terrible such as undiagnosed cancer. This was in spite of my best and consistent efforts to seek help from my GPs.

After initial review Alecia formulated an Endo Action Plan with me that focused on the next 3 months of treatment. I have the added support of a nurse. I was sent for Ultrasound and Bone Scan. I was also given a Chronic Health Plan to access additional Medicare rebated treatment from a Dietitian and Pelvic Physio. Following findings of endo growth, adhesions on my ovaries

and Adenomyosis via Ultrasound I was referred to a Gynaecologist. I have just had my 3 month review and am experiencing definite health improvements and feel confident that with the care that I am receiving I will continue to improve.

Through Thrive I have attended their Endo First Aid workshop. This was a wonderful way to update my own knowledge of my condition and hear about current treatment from Alecia. Exercise Physiologist Cherie was wonderful at teaching us ways to support and help ourselves through movement, postures and breathing activities. Hearing from other sufferers drew my attention to symptoms that I had forgotten or just wasn't in tune with because I have been living with them for so long, which means these can be addressed also.

The current referral system to a gynaecologist is expensive, takes too long (generally with long wait time over 3 months), and is often a rushed experience focused on surgery or birth control, leaving too many other symptoms unresolved. I have found referrals to other specialists (gastroenterologist/immunologist to name a few), following a similar path and do not connect the range of symptoms that an Endo sufferer has, leading to time and money spent chasing individual symptoms that are best looked at together, in a holistic approach.

All in all, this is the exact model of health care that I want to see for all sufferers of Endo and other health issues for women. The time and effort saved for myself, by accessing care through a knowledgeable GP and team, is time and money given back to me so that I can be well in a shorter time frame. This would also have positive impacts for our health care system.

Thrive Clinic, thank you, you have been a 'God send' and I'm not a religious person, I'm just so grateful to have found you.

Kindest,

B

Endometriosis Journey C.T

Early 2022 I went to my local GP due to having the following symptoms:

Heavy and painful bleeding, severe constipation, pain with bowel movements, throwing up / nausea, fevers, bladder pain/ issues, fatigue, ovarian pain, shooting pain in the groin and legs, lower back pain, severe bloating, pain during penetration & sex and recurring UTIs.

My GP sent multiple referrals through to the Flinders Gynecologist and Urologist. I saw the Urologist who couldn't come up with any answers as to why I had 9 UTIs within the first 6 weeks of having my daughter. Which then led me to seeking help from SHINE SA. We did blood tests to try to figure out what was causing the issues I was having. The blood tests weren't conclusive to what was causing the issues.

It took me 18 months to have an appointment with a Gynecologist. I did a lot of research on Endometriosis leading up to the appointment as I suspected this was my issue. I had multiple appointments with the Gyne, they did multiple physical exams and ultrasounds. They said they had no clue why I was having the pains I was having and they did not believe it was Endometriosis. I had multiple ER admissions due to the pain I was in. Eventually in October 2023 I had an emergency diagnostic laparoscopy. 6 weeks post operation I received a phone call to confirm my diagnosis of Stage

IV Endometriosis, found on both ovaries, bladder and uterus.

In September 2023 I was referred to Dr Alecia Macrow at the Thrive clinic in Glenelg via my grandmother. She saw an article in the Sunday Mail about the Endometriosis clinic. My family was concerned about the lack of care I was receiving and thought I should get a second opinion. When I filled out the paperwork for my first appointment I was in shock, the questionnaire asked all these questions that I had never been asked from the other professionals I saw. I spoke to Dr Macrow about the concerns that I had. For the first time I had a doctor who listened. I finally felt like my voice had been heard. I remember telling her I was worried that when I went for my surgery that the results would come back as nothing, that it was all in my head as the gyne made it out to be. She reassured me and said even if it wasn't Endo she would work with me to figure out what was going on.

Once my diagnosis was confirmed I informed Dr Macrow, she set up an appointment to see her ASAP. We started making a care plan that consisted of appointments every 3 months with Adelyin the Nurse followed by an apt. with Dr Macrow. There was a case conference held with a Pelvic Physiotherapist, a Pharmacist, Exercise Physiotherapist & Gastroenterologist.

I saw the Pelvic Physio twice a month for 3 months, I learnt how to relax my pelvic floor muscles. Dr Macrow spoke to the Gastroenterologist on my behalf to work out a plan to help with my severe constipation. I attended the Endo First Aid program with Dr Macrow and Cherie, the Exercise Physio. I learnt a lot about Endo and how to manage symptoms and flare ups through breathing exercises, yoga and stretching.

The Pharmacist came to my house, we spoke about the medications I was on at the time. I spoke about my concerns of wanting to come off of the antidepressant and antipsychotics I was on due to the side effects of being on them for 5 years. Dr Macrow and the pharmacist spoke about trying antidepressants that work on pain management as well as mental health. I started on Amitriptyline 10mg and Duloxetine 30mg for a month whilst weaning off Escitalopram 20mg and Seroquel 50mg. I have since increased the dosage of Duloxetine to 60mg. I also started using Meloxicam 15mg, a preventative for when I first notice the signs of pain & flare up, I take it once a day, for a week. I take k-fiber as recommended by the Gastroenterologist.

Since I have come off of my old medications, starting the new ones and implementing the tools learnt from the Endo First Aid, my quality of life has improved significantly. My flare ups were 2-3 weeks out of a month, with the pain being a 10/10. I spent most days on the couch curled up in pain. Now my flare ups last a few days at a time, with the pain being 6/10 on the worst

day. My bloating and constipation has improved since starting k-fiber which has improved my self confidence. My day to day life has changed significantly! I have a lot more energy now that I'm not suffering from a lot of pain.

I am still waiting for my post operation appointment with Flinders Hospital to talk about my course of treatment. I honestly couldn't have asked for a better team to look after me. I wouldn't be where I am if it weren't for Dr Macrow. My family and I are grateful for the care I have received. When I hear about someone suffering from Endo or suspecting Endo, I recommend them straight away to the Thrive Clinic.

Seven years. It took seven years to get a diagnosis of endometriosis, and later adenomyosis. These years considered of unbearable pain, numerous hospital trips, countless days missed of school and work, blood tests, trans-vaginal ultrasounds (oh such a joy to receive from the age of 14), packets and packets of opioid pain relief that only just took the edge off, the pill (and then the mirena as the pill impacted my mental health too much), antidepressants, appointments (psychology, gynaecology, surgery consults, dietitian), three surgeries, numerous breakdowns, heat-pack burns, and of course lots of dismissal. I received my diagnosis when I was 22, almost 23 years old, yet I had been experiencing crippling pain since the age of 14.

As a disability support worker, I'm there to support and assist individuals, yet the roles were forced to be reversed when an episode of pain left me crying on the pavers out the backyard of a client I was supporting. I begged for the pain to go away so I could continue working. I spent 20 minutes debating calling my managers to help but again, I worried that I was simply just being dramatic. I managed to move a few metres to at least be inside, where I woke my client up from their nap simply from my crying. They saw me curled up on the floor, unable to move. They had to call the ambulance and my managers to come. My manager sat with me on the floor of the hallway, outside our staff office because I was in such pain I couldn't move into another room. My client paced up and down, waiting for the ambulance to come and help me. They rang SAAS at least three times to see where they were, and to let them know they could park in the driveway. My manager and colleague assisted in lifting me off the floor, and offered to assist me to the toilet. It felt degrading, but I know they meant well. My mum sat in the emergency room, waiting for me to arrive, yet ended up picking me up from work to take me home. Three hours I waited for an ambulance. Six more hours, the paramedic on the phone told me I would have to wait before they were able to assist me. The paramedic told me to take panadol and nurofen after I told him that I couldn't move. They offered me a taxi to the hospital, but I knew that if I went it would go the usual way.

The usual way consists of waiting for hours to be seen, having to ask for endone but worrying that they'll think you're drug seeker, getting a bed, waiting two hours to see a doctor, waiting another two hours to get your blood results to simply be told 'your bloods are normal, go home and make an appointment with your doctor. Take panadol and nurofen.'. They would sometimes give me a script for endone, or tell me to get an ultrasound. I learnt to not attend the emergency department when this pain would arise from an early age, and would just hope that the pain wasn't something that would actually kill me. I remember being around 15 and being given the maximum amount of endone, which hardly touched the pain, only for the doctor to tell me there was nothing more they could do and discharged me.

Only a few months prior to seeing Dr Alecia, I received my diagnosis. 'Congratulations, we found it behind your right ovary and on your bladder, here are the photos and the nurse will get your discharge papers'. I wasn't provided any support about what my next steps were, if it would come back, or what happens if I

had more pain? I did have more pain, so much more pain. The specialist told me I 'expected the surgery to fix everything', before they gave me a script for Amitriptyline and sent me on my way. Again, no guidance on how to reduce my pain or discussion around the fact I did not want to take this medication. I took it, and suffered from severe agitation and suicidal ideation.

I had been experiencing crippling pain since the age of 14. 'Oh that's normal', 'it's just growing pains', 'just have the pill to stop your period', 'it's all in your head', and 'you're being dramatic' were all statements I had been told by doctors and specialists over the last ten years. I had an emergency doctor refuse to give me pain relief as the pain was 'in my head'. I had to fight for a laparoscopy within the public system as the specialist didn't believe I had it, and when they didn't find anything I believed I was just 'dramatic', and 'weak'. The next specialist I saw gave me a script for the pill (I already had the mirena) before telling me that I 'must not be in that much pain' when I expressed I didn't want to be on two contraceptives. I began to worry about potential flares and would bring my TENS and opioids everywhere I went. I cried to my partner and friends about the potential of having a flare up on my wedding day.

I cried on the way to my appointment with Dr Alecia, as my past experiences played-back in my head. I also cried after my appointment, but for a different reason, I had finally been heard. Dr Alecia listened to my entire history, experiences, and symptoms. She gave me detailed information on how different elements, such as diet can heighten the symptoms. She gave me information on how I could work holistically on my pain instead of just giving me a script. She listened. She cared. She validated.

I found out through an ultrasound that I had two mirenas instead of one due to my gynaecologist not removing the old one as she simply 'didn't see the strings' (it stated on my operation description the old one needed to be removed before another was inserted). I was distraught. I was anxious. What are the implications of this? What if I need another surgery? What if it's septic? What if it impacts my fertility more? They were some of the immediate thoughts that ran through my mind. I immediately reached out to Dr Alecia, who responded the same day and told me there were no serious implications, and to come in the following week. She was able to calm my racing thoughts, and reassure me that I would be okay. Dr Alecia re-referred me to the gynaecologist responsible for this issue, and I was able to have both mirenas removed and another inserted under anaesthetic.

This removal came with issues of its own. I experienced severe pain after waking up from the anaesthetic which required fentanyl and the nurses to wonder if I was bleeding internally. I had no follow up with the surgeon. A month later, I ended up calling an ambulance again after turning white, almost vomiting, and collapsing with pain. I called SAAS at 2pm. I waited two hours before my mum and grandpa assisted me into the car. I was discharged at 2am, and my mum celebrated her birthday by eating an egg sandwich at midnight because she hadn't eaten. I explained what had happened after the surgery, my diagnoses, that

I had some bleeding, and no one had checked my mirena since the surgery. I watched the doctor google adenomyosis (I know this as I saw the image that pops up on google when you type it in), before she sent me home with a prescription of endone. Nobody checked my mirena.

The next day my friend drove me to Dr Alecia, which allowed me to take my pain relief. Dr Alecia told me I had never looked so pale. Dr Alecia was the first doctor to check my mirena. It was half out of my cervix, I had birthed it. I wish I could describe how I felt when this occurred. Sad. Disappointed. Frustrated. All of the above. Dr Alecia reassured me. She removed it before talking about my options going forward, knowing (and respecting) that I didn't want to go on the pill. We booked a mirena insertion for two weeks after she rearranged her schedule to fit me in. 'I cannot believe how kind she was, and how much she listened' my friend said after the appointment. Dr Alecia messaged me that night to ensure I was okay, and again checked in with me after the weekend. She listened. She cared. She validated.

I participated in the first Endo First Aid, where I was able to meet other individuals with the same experience as myself. I was able to learn different positions to put myself in to try and relieve the pain, as well as creating a plan for strategies to use depending on the levels of pain. Dr Alecia and I created goals for myself and pain, including reducing the amount I was having to take opioids. I was supported to access a pelvic floor physio, and an exercise physiologist. Dr Alecia and Adlyn completed a case conference to discuss my care with these professionals, which enabled them to understand my story. I was thankful that I wasn't required to reshare my story for the billionth time, with fear of what the other person may be thinking.

I've been able to send emails to Adlyn, at any moment, about anything, and I know that I'll get a response full of compassion and care (and potentially a follow-up phone call). She has received my many many emails, including those where I've stated 'Honestly so fed up and I'm over it. It's gotten to the point where I'm wanting a hysterectomy.', and others that share the positive moments such as 'Also haven't had a flare up this month!'. Adlyn has listened to every single email, and responded to every single one. It is truly beneficial to be able to reach out to a professional and know that their response is full of genuine compassion and validation.

My bedside table is still full of opioids for easy access in case I had a flare that rendered it impossible to move, but I haven't had to touch them for at least four months (I'm actually ready to put them away in the medicine box). I've reduced the amount of anxiety I have surrounding the potential of a flare up, and feel comfortable being able to manage any pain without having to have opioids. I'm confident that if the pain increases or I have to have another surgery, that Dr Alecia will be there on that journey, and have case conferences with my care team. Dr Alecia holds the patient at the centre of her work, and works alongside us to provide us support and care. We are heard, and provided with a wealth of knowledge.

I was asked to write 3-4 paragraphs of my journey and experience, but that simply wasn't enough. The journey was complex, exhausting, and traumatic but I feel reassured knowing that I'm fortunate enough to be under the care of Dr Alecia. There are not enough 'thank yous' or letters I could write to express how grateful I am that I was able to access the Endo Clinic and be supported by the team at Thrive.



- Tash Stevens