



# Submission to the Parliament of South Australia's Select Committee on Endometriosis

From the Commissioner for Children and Young  
People's Period Justice Working Group

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May 2024



**period justice.**

**To:** Parliamentary Officer  
Select Committee on Endometriosis

**Email:** [scendo@parliament.sa.gov.au](mailto:scendo@parliament.sa.gov.au)

## Commissioner's Foreword

Thank you for the invitation to provide a submission to the Select Committee on Endometriosis. Rather than prepare my own submission in response to your invitation, I am pleased to present this submission on behalf of the Period Justice Working Group.

It is critical that the Select Committee on Endometriosis consider the rights, views and experiences of children and young people in South Australia. This submission comes directly from young people, and I particularly thank Valeria Cacerez Galvez who took the lead in writing this submission.

As Commissioner for Children and Young People, my role is to promote the rights, interests and wellbeing of all children and young people in South Australia. Since 2017, I have engaged with thousands of children and young people across the state.

My 2021 *Menstruation Matters* report focuses on the impact of menstruation on children and young people's wellbeing, participation and school attendance, and was informed by over 3,000 survey responses from South Australian children and young people.<sup>1</sup>

My 2022 *Issue Brief on South Australian children and young people's experiences of living with chronic illness* provides insights into the impacts of a range of chronic illnesses, including endometriosis, on young people's rights and wellbeing, with a particular focus on school settings.<sup>2</sup>

Throughout 2023, I worked with a group of young people who are passionate about menstrual health and period justice to organise South Australia's inaugural Youth Period Summit. The Period Justice Working Group was established following the success of the youth-led summit.

I would welcome the opportunity to further assist the Committee as the Inquiry progresses. In particular, I would like to express interest in supporting young South Australians to present oral evidence to the Committee. Please contact [commissionercyp@sa.gov.au](mailto:commissionercyp@sa.gov.au) to discuss.



**Helen Connolly**

Commissioner for Children and Young People  
South Australia

## About the CCYP Period Justice Working Group

The Period Justice Working Group is a group of young people between 11 and 23 years old, led by the Commissioner for Children and Young People (CCYP) SA.

Since forming in August 2023, 22 young people have attended meetings and been involved in different capacities. The group is diverse and includes an Aboriginal young person, a young person from a refugee background, a young person with a lived experience of homelessness, 5 young people who speak a different language at home, 4 young people who identify as queer or gender nonconforming, and 2 young people who identify as neurodiverse. Of the young people involved 1 is a primary school student, 14 are high school students and 7 are currently studying at TAFE or University. All young people involved use she/her pronouns.

The Working Group works on various projects relating to period justice. Period justice is about challenging and addressing systemic issues that create injustice for those who menstruate, impacting their ability to engage equally in education, employment, sport and social activities.

Many young people report facing barriers to managing their periods, including not having the education to understand what is happening to their bodies, not having access to affordable products, not knowing how best to deal with their symptoms, and not knowing when they need to go to the doctor for help. Social, cultural and sexual prejudices all restrict young menstruators' fulfilment of their rights.

## Introduction

We are very grateful to have an opportunity to have our voice heard in this parliamentary inquiry. We know that addressing menstrual-related conditions, which have historically been ignored by medicine, is important in achieving period justice.

Endometriosis has been under researched and unacknowledged for far too long. The condition affects about one in ten people who menstruate, yet diagnosis is often delayed – the average endometriosis sufferer has a 7-year gap between the onset of symptoms and their diagnosis. Because of the diagnosis gap, many sufferers aren't diagnosed until their late 20s or 30s. However, young menstruators can experience endometriosis symptoms from menarche, their first menstrual cycle.

Epidemiological data is starting to show that young generations of menstruators are being diagnosed with endometriosis at a younger age than previous generations – this signals that people are being diagnosed earlier and with less of a diagnosis lag which is a positive sign.

We are very glad the South Australian Parliament is taking action on endometriosis with this Inquiry, and we cannot wait to see the meaningful action taken as a result. We want our submission to encourage the Select Committee to increase their focus on the experiences of young people with endometriosis and pelvic pain conditions, because young people have special healthcare and social needs.

Young people, as shown within our group, are passionate about period justice and want to see positive change in this area. We also want to inform you of the important work we are doing with the Department of Education to ensure our health curriculum is fit-for-purpose, relevant and meeting the needs of young people in terms of menstruation education.

We have divided our submission in three key themes:

- 1. Counting young people in;**
- 2. The education we want; and**
- 3. The impacts of endometriosis on young people's participation.**

We do also note that in this submission we will be using inclusive language as to not exclude the valid experiences of transgender and gender diverse members of the community with endometriosis and pelvic pain.

## **1. Counting young people in**

We strongly believe that the experiences of young people with pelvic pain and endometriosis should be considered in this inquiry. Young people have unique experiences and needs regarding pelvic pain and endometriosis that deserve your consideration.

Because of the diagnosis lag with endometriosis, many young people with endometriosis are not diagnosed until they are in their 20s or 30s, but their experiences of pain and endometriosis symptoms are valid and can begin at one's first period, also referred to as menarche. Researchers at the Flinders University report that the average age of menarche in Western countries is steadily decreasing, with the current age of menarche currently being 12.5 years.<sup>3</sup>

Many young people who have endometriosis symptoms but are not yet diagnosed, find 'not knowing what is wrong with them' difficult to cope with. We need to address this issue at the root cause by reducing the diagnosis time frame and upskilling healthcare workers to better recognise the symptoms of endometriosis.

Since endometriosis is a progressive condition, meaning it can get worse over time, and co-morbidities are common, many young people experience compounding symptoms and long-term health effects. This is another critical factor to consider as young people need to have the skills and knowledge to describe their symptoms and communicate and advocate for themselves when seeing healthcare professionals. Young people need to be empowered to seek healthcare and have healthcare services accessible to them both socio-culturally and financially.

Our group would like to see more research funding and resourcing for endometriosis. We want to see treatments for endometriosis that aren't birth control. We note that birth control can be a sensitive topic for many young people to discuss with family and healthcare professionals, even if it is being used for a non-contraceptive purpose. We want to see treatments that actively target endometriosis tissue rather than just suppress

symptoms. We also need governments to invest in research around young people's experiences with pelvic pain and endometriosis. In particular, we need to better understand barriers to seeking care and the epidemiology of endometriosis in young populations.

Our group noted that being diagnosed with endometriosis at a young age can bring up some difficult conversations about fertility. It is very hard for young people to think about fertility at a young age and make decisions for their future, so specialised psycho-social support for young people with endometriosis and pelvic pain conditions is needed to remedy these hard moments.

### **Quotes from Period Justice Working Group Members**

"Young people's experience of pelvic pain and endometriosis are valid. At a young age many sufferers do not yet have the language and knowledge to seek healthcare - this does not mean their experience should not be considered"

### **Quotes from young people from the Commissioner's Chronic Illness Survey**

"Formal diagnosis for endometriosis often occurs 7-10 years after seeking assistance. Many school age sufferers will be suffering but not have a formal diagnosis so there is not an opportunity for a agreed support plan to be put in place."

"chronic illness doesn't fit in a schedule and often for young people with conditions such as endometriosis it is extremely difficult to advocate for yourself as teachers, peers etc are often dismissive and don't understand the level of pain, discomfort you may be experiencing"

### **Quotes from young people from the Commissioner's Menstruation Matters Report**

"Most days I'm in bed due to endometriosis. I was 20 before they found out that I had endometriosis and I had been suffering since I was 9, but not one doctor believed my pain!"

## 2. The education we want

The Period Justice Working Group has been working with the SA Department of Education to update curriculums around health, puberty and healthy relationships over the past six months. As a group we have developed some recommendations to shape the future of menstruation education and SA curriculum to be relevant, appropriate and useful for young people.

- a. Menstruation Specific Education** – The Period Justice Working Group strongly endorses the inclusion of education around menstruation in all curriculums. We believe that young people have the right to understand the bodily process occurring in their own bodies and the right to have the skills and knowledge to menstruate with dignity. We advocate for menstruation education to include information around managing menstruation symptoms (different products) and also knowing what levels of symptoms, such as pain, require medical assistance and how to seek help. By empowering young people with the language and knowledge to understand their bodies, we believe young people can become advocates for their health and experiences.
- b. Including All Genders and Sexes** – The consensus view of the Period Justice Working Group is that menstruation education should be delivered to all young people regardless of their gender or sex. We have heard from many students that menstruation education, if it is delivered, is only delivered to students who menstruate or who identify as female. We believe it is crucial for all young people to have knowledge around menstruation even if they do not menstruate themselves. We want all young people to be empowered to look after themselves and those around them – everyone has someone in their life who menstruates and likely has a person in their life with endometriosis. By giving education to all people, we can debunk myths around periods and also about period-related conditions like endometriosis. By validating the experiences of pelvic pain, we can address stigma and increase awareness in the community.
- c. Separate Menstruation from Sexuality Education** – We strongly believe that menstruation education should be separate from sexuality education. In multiple discussions our group has noted that including menstruation when talking about sex makes menstruation more taboo. Moreover, having conversations just on menstruation and health at a young age without reference to sex by separating health and anatomy from sexuality education makes the education more age-appropriate and relevant to young people.
- d. Build Knowledge Over Time** – We want menstruation education to be built over time rather than a once off conversation. As stated above, by separating menstruation from sexuality education, we can develop a curriculum that is age-appropriate and relevant to young people of different ages.

- e. **Resources Available** – We want resources readily available to students at schools and community centres. Posters and written resources, as well as in-depth and interactive sessions like the Periods, Pain and Endometriosis (PPEP Talk) Program are important to disseminate information and improve health literacy.

The Period Justice Working Group strongly believes that we need to train the next generation to acknowledge period-related conditions as valid and change the culture which leads to endometriosis being dismissed in our health system and community. We note that we have heard stories from friends and community leaders that one of the contributors to the diagnosis lag is medical gas-lighting and healthcare professionals not taking young people's pelvic pain seriously.

We think it is important to equip all young people with the education and language they need to advocate for themselves and others who struggle with endometriosis. As highlighted in the CCYP Menstruation Matters Report, many young people have their pain dismissed or trivialised, and many note the considerable amount of energy it takes to “soldier on”.

It is also important to ensure conversations around menstruation and endometriosis are not labeled as “a woman's issue” but rather a community issue. This incentivises leaders, institutions and workplace to create policies and support for people with endometriosis. It also limits stigma by ensuring our community is aware of the seriousness of endometriosis and helps to break down barriers to seeking and accessing healthcare and support.

#### **Quotes from young people from the Commissioner's Menstruation Matters Report**

“So many boys grow up to have no understanding of periods, which can make them unsympathetic in the workforce and in relationships, this negatively impacts the people around them who have periods.”

“It was less embarrassing to be taught in single gender classes. However, it is essential for all genders to learn about periods so they can support people with periods throughout their life.”

“Education should really go more in depth about what is a normal and abnormal period cycle and how much pain is too much. This will really help young girls recognise when they might have a period related condition such as endometriosis for example, and get that investigated sooner [rather] than later.”

“I was taught women must soldier on despite the [period] pain. I've only taken a few days off schools from the pain, because I struggled to get out of bed”

### Quotes from Period Justice Working Group Members

“By having education in all schools, we are making sure the next generation of doctors have [the tools] they need to break stigmas and support people [with endometriosis]”

“Giving young people knowledge helps them to seek out support, empowers and gives young people autonomy. Giving back that power so they can vouch for themselves”

### 3. Impacts of endometriosis on young people’s participation

In this section we would like to expand on the terms of reference “the impacts to employment of sufferers and employer best practice in supporting women with the condition”. We need to break down stigmas around pelvic pain so workers of all ages and particularly young workers can negotiate working arrangements that are suitable for chronic health conditions. We think the inquiry should also focus on the impacts of endometriosis on participation more broadly, and include education and community engagement as well as employment as a marker of quality of life and area for support.

Members of the Period Justice Working Group all have friends or themselves report missing out on schooling, work and social life because of pelvic pain conditions such as endometriosis. We note that pelvic pain conditions like endometriosis have a range of symptoms like chronic fatigue which influence one’s ability to fully participate in community life without adequate socio-cultural support. Our group agreed that we need to take a more proactive approach & create safe spaces for conversation. There is a need to normalise conversations (rather than waiting until urgent to share) and tailor support to individual needs.

We identified two areas where young people with pelvic pain and endometriosis could be supported: educational institutions and community sports.

- a. Educational Institutions** - Many young people spend significant proportions of their time at school or university, this is their key non-home environment. We note that period pain is rarely acknowledged or taken into account in relation to young people’s school performance or attendance. Significant numbers of children and young people reported in the Menstruation Matters Report that they missed school due to their period. Most of these young people reported missing less than 5 days per year. However, a smaller, but not insignificant number reported missing more than 20 days each year. For these young people, their lost school days meet the threshold for chronic absenteeism. Absenteeism was caused by a variety of factors including difficulty managing period pain and accessing pain relief while on their period at school.



Many of our group members note that primary and secondary schools have official and unofficial rules around accessing bathrooms and lockers at certain times of the day. In the Menstruation Matters Report, children and young people described not being allowed to leave class at certain times, sometimes even when they announced that they were on their period in front of the class – something most students were uncomfortable doing.

Because of this, we believe targeting policies and health promotion programs should occur in educational institutes that are targeted towards young people. We would like to see educational institutions having the resources to provide physical and social support to young people with chronic health conditions such as endometriosis.

An example our group came up with is having readily accessible heat packs at schools. Heat packs are a non-invasive and effective treatment to suppress pelvic pain associated with menstruation and endometriosis.

Moreover, we believe educational institutions should have policies around supporting students with chronic pain that students are aware of. We want to see greater flexibility embedded for students with chronic health conditions: special provisions for exams, flexibility with assessments, greater access to the ability to study from home and extra support to compensate for classes missed for health reasons. We also would like to see teachers and support staff being given training on how to support students with chronic health conditions and using a compassionate approach to workloads.

### **Quotes from Period Justice Working Group Members**

“We need leniency on assignments and understanding when people need to take time out. I hope we can come to a place where people can be truthful and build a culture that destigmatises pelvic pain.”

### **Quotes from young people from the Commissioner’s Chronic Illness Survey**

“There was no support at school for my pain. No one knew what was happening and nothing helped... More schools need to be educated about reproductive chronic illnesses such as Endometriosis, PCOS, Fibroids etc.”

“Trying to explain or not feeling comfortable to explain needing to leave class or needing extensions due to physically not being able to complete the work in time was really difficult - I also found this an extra layer of difficulty as not only it’s a chronic illness but more so because it is related to periods which often make people uncomfortable or is stigmatised so much.”

### Quotes from young people from the Commissioner's Menstruation Matters Report

"During the early days, I try to avoid moving because of my cramps. Unfortunately, at school it is very hard to stay in a consistently cramp-free position."

"I avoid moving..... my cramps get really bad so that I have to skip school and do nothing for a couple of days..... I avoid going to other people's houses, parties."

"Being more inclusive and more educational would have helped. Free period products and free pain medication or even heat bags at school to teach girls that it is okay to treat their period pain - even at school."

- b. Community Sports** - Some of our group members mentioned that they have friends who quit community sports because of their periods and the symptoms accompanying menstruation (pain and fatigue). Period pain affects young people's ability to participate in society and can make it hard to do extracurricular activities which are important for mental health and community mindedness which we believe should be just as valued as participation in work and education. The CCYP has done research and advocacy into creating [period friendly sporting clubs](#) which are relevant to discussions of making our society more accommodating to people with endometriosis.

As noted in the CCYP Menstruation Matters Report, period symptoms like "a lack of energy, severe cramps, pain and other physical symptoms such as headaches, vomiting and nausea" can be barriers to young people's participation in sport and physical activity.

### Quotes from young people from the Commissioner's Menstruation Matters Report

"I avoid all sports because it's uncomfortable and the fast paced exercise makes me dizzy due to blood loss as well as headaches, dizziness and nausea being some of my symptoms. I also can't move a lot on my first and or second day due to pain so I stay home from school very often."

### Quotes from young people from the Commissioner's Chronic Illness Survey

"I was pressured to join sports day events (every student had to do a minimum amount of events) which I didn't feel physically capable of doing. None of my friends understood my illnesses and drifted away from me as I was always unwell, so I lacked a support system of peers. Managing comfort levels to mitigate symptoms in a classroom can be difficult. For example, I can't regulate my temperature well, and classrooms were often stuffy and hot."

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<sup>1</sup> Helen Connolly, Commissioner for Children and Young People South Australia, *Menstruation Matters: The impact of menstruation on young people's wellbeing, participation and school attendance*, 2021, <https://www.cyp.com.au/wp-content/uploads/2022/03/Menstruation-Matters.pdf>.

<sup>2</sup> Helen Connolly, Commissioner for Children and Young People South Australia, *Issue Brief: South Australian children and young people's experiences of living with chronic illness*, 2022, <https://www.cyp.com.au/wp-content/uploads/2023/04/Issue-Brief-Chronic-Illness.pdf>.

<sup>3</sup> Olivia Bellas, et al, "Staff perceptions of support for early menarche in Australian primary schools: a qualitative study", *Sex Education*, 2023, <https://doi.org/10.1080/14681811.2023.2275595>.