



Endometriosis

Western Australia Inc.

ANNUAL REPORT

2022

For the financial year ended 30 June 2022

Endometriosis Western Australia Incorporated

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SECTION 1 – ABOUT US

OUR VISION

To provide individuals affected by endometriosis, including their family and carers, with access to the best quality information, care, and support.

OUR SERVICES

Support

- We run an online peer-support group, bi-monthly educational workshops, and social events for people with endometriosis in WA.

Awareness and education

- We raise awareness and provide education via online platforms and community events. We advocate at a state and national level for people with endometriosis in WA.

Research

- We support and promote research into the causes, diagnosis, prevention, and management of endometriosis.

OUR HISTORY

In 2013, there was no support group for those with endometriosis in the Perth metropolitan region. Recognising the absence of social and cultural support 'Endometriosis Perth Sisterhood of Support' (EPSS) was founded.

With momentum, in 2015, EPSS expanded reach to a wider community across Western Australia (to both online and offline members). We coordinated and facilitated regular face-to-face meetings, either educational, social or a mix of both to improve the wellbeing of our members and wider community. These events are free, run by dedicated volunteers with the occasional in-kind support of allied health professionals. Some examples of our presentations given at events can be accessed on our [YouTube channel](#).

EPSS began advocating in 2016, raising the public awareness of endometriosis in Western Australia via marketing and social media campaigns. We have continued to be active, providing online peer support services and facilitating the successful running of six events per year. We continue to film our larger educational sessions to make the information readily accessible to those unable to attend.

In recognition of this work to date, we have been fortunate to be nominated as finalists twice in the global [WEGO Health Awards](#) in the past, as well as receiving the ConnectGroups [New & Emerging Support Group Award](#) in 2017, and ConnectGroups 'Online/Facebook Support Group Award' in 2021.

Since we have been founded, we have continued to demonstrate value to our members and wider community in Western Australia. We continually receive consistent positive feedback from members, with high levels of member engagement, retention and referral. As a result of these successes, we incorporated as 'Endometriosis Western Australia Inc.' and obtained deductible gift recipient endorsement in 2019. In 2020, we received our charitable collections licence. In 2021, to be inclusive of the diversity in our member base and community, we rebranded the name of our support group to 'Endometriosis Western Australia Warriors'.

OUR PEOPLE

Patron

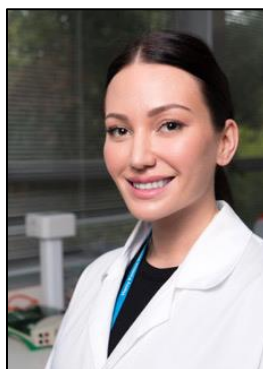
Ms [Cassandra Michelle Rowe](#) MLA
BA; AdvDip (FinServ); Dip (FinServ); Dip (Screenwriting)
Member for Belmont, Australian Labor Party



Board of Management 2021-2022



Kiera Collier
President



Akaiti James
Deputy President



Rebecca Kale
Treasurer



Tegan Phillips
Secretary



Monique Alva
**Board Member & Operations
Coordinator**



Katya Fleming
Board Member

Board Members (Outgoing during 2021-2022 financial year)



Joanne McCormick

President (until September 2021)



Linh Nguyen

Treasurer (until September 2021)

Ambassadors

Claudia Wright (until February 2022)

Operational Volunteers

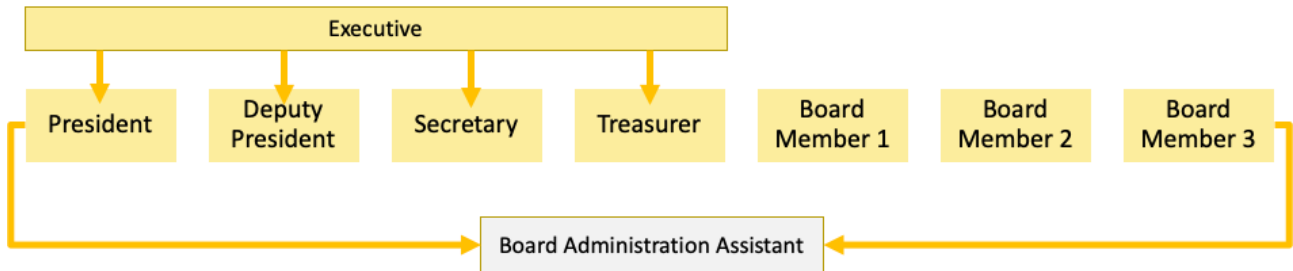
Name	Position(s)	Name	Position(s)
Monique Alva	Operations Coordinator	Tessa Pinkerton	Facebook Moderator
Charmaine Galea	Facebook Administrator	Christine Trimboli	Fundraising/Public Events Manager
Emma Atherton	Facebook Moderator Events support	Chloe Hill (until May 22)	Facebook Moderator
Taylor Lynch	Events Coordinator	Rebecca Kale (until Nov 21)	Facebook Moderator
Emma-Louise McDowell	Facebook Moderator	Tegan Phillips (until Oct 21)	Events Facilitator
Katia Fernandes	Social Media Officer	Holly Warner (until Jan 2022)	Facebook Moderator
Katya Fleming	Facebook Moderator Event Facilitator	Katie Stewart (until Dec 21)	Facebook Moderator
Bianca Dawson Pipp Hamilton	Facebook Moderator Facebook Moderator	Jo-Anne McCormick (until Sept 2021)	Facebook Administrator Event Coordinator Event facilitator Social Media Administrator

STRUCTURE AND MANAGEMENT

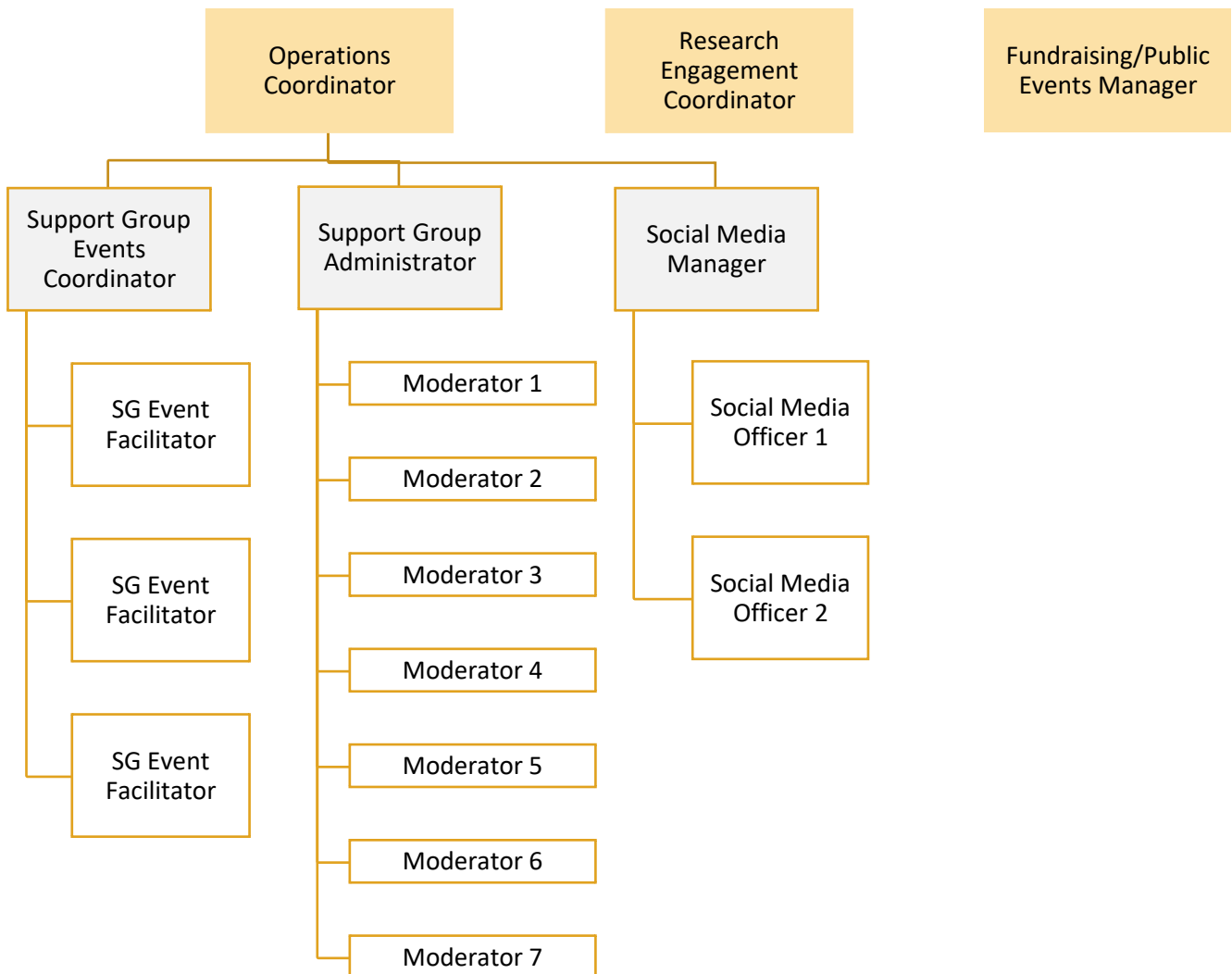
Endometriosis Western Australia Incorporated is:

- Incorporated under the *Associations Incorporation Act 2015* (WA);
- Registered as a 'health promotion charity' with the Australian Charities and Not-for-profits Commission (ACNC);
- Licensed in Western Australia under the *Charitable Collections Act 1946* (WA).
- Licensed in Tasmania under the *Collections for Charities Act 2001* (TAS).

Board



Operational Team





Ms Cassandra Michelle Rowe MLA

*BA; AdvDip (FinServ);
Dip (FinServ); Dip
(Screenwriting)
Member for Belmont,
Australian Labor Party*

SECTION 2 - COMMENTS FROM OUR PATRON

As Patron of Endometriosis Western Australia, I would like to congratulate and thank the President, Board and Members for their fantastic work over the past year.

It has been wonderful to see EndometriosisWA go from strength to strength, achieving some incredible milestones.

Success at the ConnectGroups WA 2021 Peer Support Groups Award Presentation Evening last October, winning the 'Online/Facebook Support Group Award' was a sign of things to come. The announcement of the EndOrigins project in November was very exciting. I cannot wait to hear about the outcomes of this research collaboration. The #YellowForEndo social media campaign for Endometriosis Awareness Month provided greater exposure for the organisation and attracted more supporters to the cause. The \$58 million commitment made by the Federal Government for people living with Endometriosis is a big step forward in terms of funding and hopefully signals a broader acknowledgement for the need to invest in this space.

I encourage you all to continue your crucial advocacy and support work. Your efforts are making a considerable difference and the organisation's capacity and influence is growing every day. I am so proud to be the Patron of EndometriosisWA and look forward to celebrating the many future achievements to come.



Kiera Collier
Endometriosis Western
Australia President

SECTION 3 - PRESIDENT'S REPORT

I am pleased to present Endometriosis Western Australia's Annual Report for 2021 - 2022 – a transformational and productive year for the organisation.

The organisation continues to thrive as we navigate the transformation from a small grassroots support group to a state-wide Incorporated Association. EndometriosisWA works to support the community across three main areas: Support, Awareness and Education, and Research. The many milestones and achievements of this financial year are a true testament to the dedication of our volunteers and engagement and passion of our member base. This report outlines key milestones, such as the announcement of the EndOrigins Biobank project, membership to the Australian Coalition for Endometriosis, advocacy for updates to the RANZCOG guidelines and improvements to tertiary health services, collaboration on the EndoZone project, and the continuation of our educational events and online support group 'Endometriosis Western Australia WArriors'.

I would like to thank EndometriosisWA's Board Members and volunteers for their dedication and diligence over the past year. Endometriosis Western Australia runs on the passion and integrity of its volunteers, your commitment to the endometriosis community is admirable. In particular, the Board gives thanks for the years of contribution of outgoing Board Members during the 2021-2022 financial year, Joanne McCormick (Founder and outgoing President, resigned September 2021) and Linh Nguyen (Treasurer, resigned September 2021).

EndometriosisWA are proud members of the World Endometriosis Organisations, ConnectGroups – Support Groups Association and most recently, the Australian Coalition of Endometriosis (ACE). We were delighted to announce our membership to ACE in February 2022, joining current members EndoActive, Pelvic Pain Foundation of Australia, Endometriosis Australia and QENDO. EndometriosisWA hopes our membership to ACE will help Western Australian endometriosis patients have their voice included in future planning for disease prevention, management, research and treatment at a national level. EndometriosisWA looks forward to strengthening our partnerships with other support and endometriosis organisations to work towards a better quality of life for all endoWArriors.

In March, EndometriosisWA were thrilled to see the announcement from the Australian Federal Government of \$58 million towards initiatives supporting people living with endometriosis. EndometriosisWA would like to thank the dedication of the many individuals and organisations that have advocated to make this a reality. We are proud to be members of the Australian Coalition for Endometriosis and look forward to representing the voice of Western Australians living with endometriosis. Whilst this funding is a huge step forward for the endometriosis community, we would like to see a similar commitment from the WA State Government. Additional funding is required to improve access to excision surgery in the public system by increasing the number of suitably trained (AGES) advanced laparoscopic surgeons in

WA tertiary hospitals. This would reduce the already prolonged wait times which are expected to increase with COVID-19 reaching WA and delaying services.

With the conclusion of our 2019 – 2022 Strategic Plan this year, in the coming months EndometriosisWA will be focusing on the development of a renewed Strategic Plan. This review will be largely based on feedback from our member base, with core elements for consideration including increasing our presence in the community, expansion of our volunteer team and most importantly, supporting and advocating for our members at a state and national level.

EndometriosisWA is thankful to be supported by the generosity of our local community. In particular, I would like to thank the organisers and attendees of 'SubieFest' for their incredible donation of \$15,000. The funds raised will go a long way in ensuring our organisation can continue to run, provide support to those living with endometriosis and continue to advocate for improved services for endoWARRiors.

Lastly, I would like to thank our members for supporting and advocating for Endometriosis Western Australia. Your ongoing support and contribution to our organisation is highly valued. We continue to endeavour to provide you with valuable services, operate with transparency and inclusivity, and look forward to advocating on behalf of the community for years to come.



Pictured: Founder and Outgoing President of Endometriosis Western Australia Joanne McCormick (R), with incoming President Kiera Collier (L)



Pictured: Founder and Outgoing President of Endometriosis Western Australia Joanne McCormick



Pictured: Incoming EndometriosisWA Board (L-R): Rebecca Kale, Kiera Collier, Akaiti James, Monique Alva, Tegan Phillips (Absent): Katya Fleming

SECTION 4 - TIMELINE & ACHIEVEMENTS

2021	Milestones	Delivery
July	<ul style="list-style-type: none"> Board succession planning 	<ul style="list-style-type: none"> Recording of 'Endometriosis & Intimacy' workshop made available on YouTube 'The Happi Study' research opportunity shared via eCommunications & support group
August	<ul style="list-style-type: none"> Celebrated 8 years of Endometriosis Western Australia WARRIORS/Endometriosis Perth Sisterhood of Support National census advocacy – increase awareness of endometriosis through the census by ticking 'Yes' to Q28 "Any other long-term health condition" 	<ul style="list-style-type: none"> First in person support group event post-COVID-19: 'Advocating for a Loved One' (also published on YouTube)
September	<ul style="list-style-type: none"> Annual General Meeting <ul style="list-style-type: none"> Founder and President Joanne McCormick steps back from the organisation after 8 years of service New Board of Management elected EndometriosisWA announced as a finalist in ConnectGroups WA 2021 Peer Support Groups Award Presentation Evening Meeting with local endometriosis specialist to discuss increased access to endometriosis services 	<ul style="list-style-type: none"> Proteomics International biomarker research opportunity shared via eCommunications & support group
October	<ul style="list-style-type: none"> EndometriosisWA wins 'Online/Facebook Support Group Award' in ConnectGroups WA 2021 Peer Support Groups Award Presentation Evening Endometriosis Western Australia WARRIORS Support Group reaches 4000 Facebook Group members EndometriosisWA announced as beneficiary for SubieFest WA 2021 Event Board Planning Day – governance and planning Participation on the NECST Network & Consumer Advisory meetings (ongoing through to January 2022) 	<ul style="list-style-type: none"> Non-surgical Treatment of Endometriosis support group event (YouTube) University of Roehampton London research opportunity shared via eCommunications & support group Curtin University Persistent Perineal Pain research opportunity shared
November	<ul style="list-style-type: none"> Endometriosis advocacy and engagement with local community at SubieFest WA 2021: stall and speech Donation of \$15,000 to EndometriosisWA from SubieFest WA 2021 event 9News Perth Interview with support group member Christine Trimboli and Deputy President Akaiti James on public health system wait times. EndOrigins project announced after obtaining human research ethics approval. EndoOrigins is a collaboration between researchers at the University of Western Australia and doctors at King Edward Memorial Hospital and is supported by the Fiona Wood Foundation and EndometriosisWA. 	<ul style="list-style-type: none"> Volunteer Appreciation Lunch
December	<ul style="list-style-type: none"> Collaboration with EndoZone. EndometriosisWA provided written articles for the new digital platform. Ongoing endorsement of the NECST Network 	<ul style="list-style-type: none"> EndoWarriors Christmas lunch with loved ones

2022 January	<ul style="list-style-type: none"> Implementation of new marketing strategy and social media graphics 	
February	<ul style="list-style-type: none"> Endometriosis Western Australia joins the Australian Coalition for Endometriosis, alongside Endometriosis Australia, QENDO, the Pelvic Pain Foundation of Australia and EndoActive. Board Workshop 	<ul style="list-style-type: none"> Naturopathy and Endometriosis Support Group Event (YouTube)
March	<ul style="list-style-type: none"> Letter sent to Health Minister Jade Sanderson advocating for increased funding and improvements to King Edward Memorial Hospital endometriosis services. <ul style="list-style-type: none"> The letter particularly highlighted the absence of a colorectal surgeon for endometriosis surgeries and included stories from our members. #YellowForEndo social media campaign for Endometriosis Awareness Month Collaboration with local endometriosis specialist, Dr Rose McDonnell to answer questions from EndoWArriors Public Statement released: <ul style="list-style-type: none"> highlighting the importance of inclusivity in the endometriosis community, call to action for increased funding in WA to improve endometriosis hospital services e.g. increased access to excision surgery, adequate number of suitably trained (AGES) advanced laparoscopic surgeons, clinical time to make a management plan, colorectal surgeon support providing an opportunity for endoWArriors to contribute to an open letter to RANZCOG with a list of suggestions to improve the current endometriosis guidelines Australian Federal Government announces \$58 million towards initiatives supporting people living with endometriosis Article in Western Independent – online publications by Journalism students at Curtin University 	
April	<ul style="list-style-type: none"> Adenomyosis awareness month educational information shared on social media Launch of EndoZone Platform 	<ul style="list-style-type: none"> Endometriosis and Medicinal Cannabis Support Group Event (YouTube)
May	<ul style="list-style-type: none"> Board and Operational Recruitment Drive President Kiera Collier attends launch of EndoZone platform in Adelaide Operational Workshop 	
June	<ul style="list-style-type: none"> Recruitment Drive Finalised Open letter containing feedback from the endometriosis community on the endometriosis guidelines sent to RANZCOG Development of new brochure by Des Hameister (pro-bono graphic design work) Website re-design via ConnectGroups Give It Forward grant (awarded June 2021) enters final stages of development. 	<ul style="list-style-type: none"> Endometriosis and Exercise Physiology Support Group Event (YouTube)

21/22 ACHIEVEMENTS

Endometriosis Western Australia works to support the community across three areas:

- Support
- Awareness and Education
- Research

Endometriosis Western Australia joins the Australian Coalition for Endometriosis



9 February 2022

MEDIA RELEASE

Endometriosis Western Australia Inc joins The Australian Coalition for Endometriosis

Endometriosis Western Australia Inc. is delighted to announce our membership to The Australian Coalition for Endometriosis (ACE). We join current members EndoActive, Pelvic Pain Foundation of Australia, Endometriosis Australia and QENDO. EndometriosisWA hopes our membership to ACE will help Western Australian endometriosis patients have their voice included in future planning for disease prevention, management, research, and treatment at a national level.

ACE is a peak consumer and advocacy body representing the needs of those with endometriosis across Australia. ACE works with various stakeholders, including the Australian Government Department of Health, to provide strategic direction and leadership to improve the outcomes, treatment, and support for people with endometriosis.

Endometriosis is a chronic disease where tissue similar to the lining of the uterus grows where it does not belong. On average, it takes seven years for patients to get an endometriosis diagnosis.¹ The disease often severely impacts relationships, productivity and the quality of life of people living with endometriosis. In the 2018 fiscal year, endometriosis cost the Australian economy \$7.4 billion in lost productivity.²

1 in 9 women, girls and those assigned female at birth have endometriosis.³ There is no cure.

Endometriosis Western Australia is a non-profit providing information and support to people living with endometriosis in Western Australia. Driven by volunteers, EndometriosisWA raises awareness, educates, and advances research related to endometriosis.

Through our membership with ACE, the implementation and review of the National Action Plan for Endometriosis can include the perspectives and experiences of Western Australians. EndometriosisWA is looking forward to strengthening our partnership with other endometriosis organisations to work towards a better quality of life for all Endo Warriors.

Kiera Collier

President, Endometriosis Western Australia

E president@endometriosiswa.org.au

W www.endometriosiswa.org.au

¹ <https://www.aihw.gov.au/getmedia/a4ba101d-cd6d-4567-a44f-f825047187b8/aihw-phe-247.pdf.aspx?inline=true>

² <https://endoactive.org.au/wp-content/uploads/29May2019-FINAL-The-Cost-of-Endometriosis-in-Australia-EY-EndoActive-Report.pdf>

³ <https://www.aihw.gov.au/reports/chronic-disease/endometriosis-prevalence-and-hospitalisations/summary>

SUPPORT

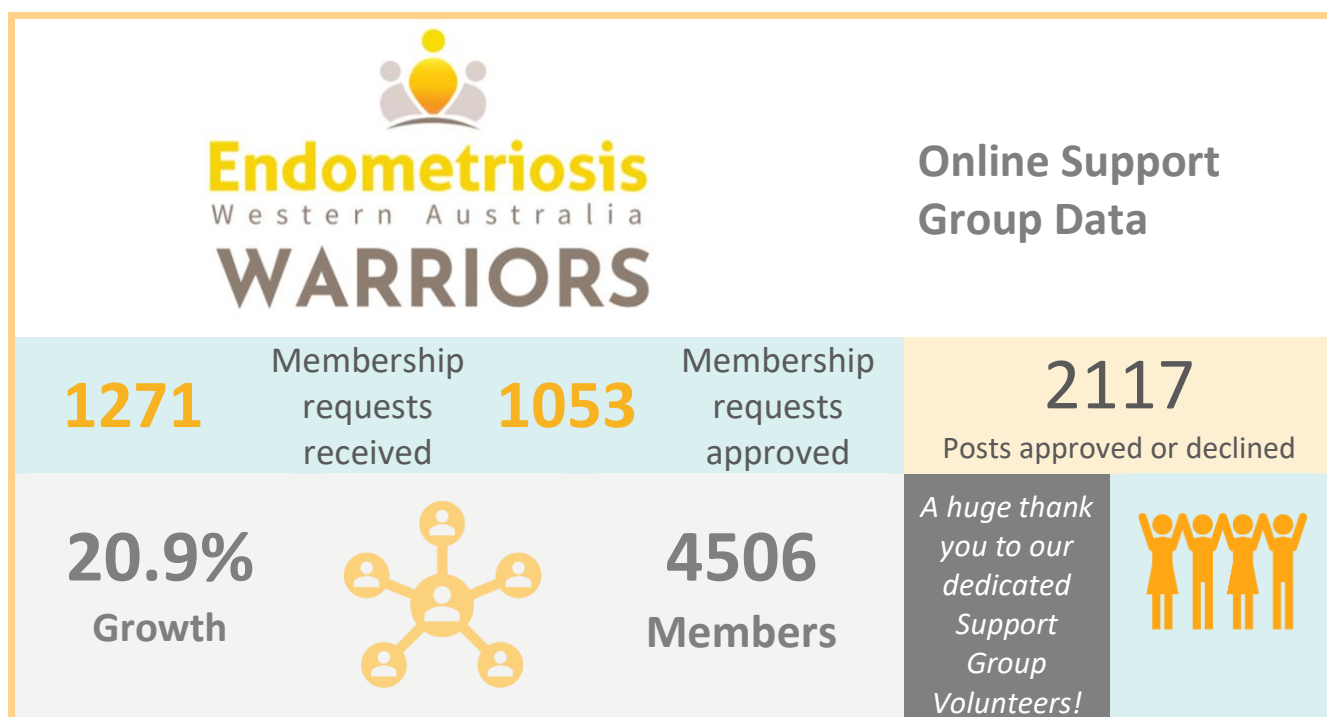
Endometriosis Western Australia WARRIORS

Endometriosis Western Australia Inc. provides online peer support to people living with endometriosis in Western Australia and people living with endometriosis who were born in Western Australia via the Facebook group 'Endometriosis Western Australia Warriors'.



The Facebook group name transitioned from EPSS to 'Endometriosis Western Australia Warriors' in January 2021 to reflect the Western Australian endometriosis community.

As of 30 June 2022, the support group had over 4500 online members, with an average age between 25-44 years. 98.7% of members are living in Australia, 1.3% reside overseas. The majority of members are located in Perth, followed by Mandurah and surrounds, and Bunbury and surrounds. 99% of members identify as female. A team of 13 volunteers supported the administration and facilitation of the group in financial year 2021-22.



Feedback from our members about Endometriosis Western Australia WARRIORS in the 2021-2022 Financial Year:

- "Thank you for having this group and providing a safe supportive space for those suffering from this horrible condition."
- "This Facebook group is very useful. I have found tons of great information. However I am not always comfortable sharing private information as I have no idea who is reading the comments."
- "It's an amazing group that made me feel like I wasn't alone and I get supported. It helped me get through my diagnosis journey and provided me with important information. I am very grateful for this group chat!!"
- "Please look into the sensitive content guideline it is way too strict!"
- "Is a great way to get perspective and better insight, especially with not feeling alone. A great way to support one another and give insight to possible treatments and causes etc"

Support Group Events

Endometriosis Western Australia Inc. coordinates and facilitates six support group events each year that are a combination of in person and online delivery. Events are a combination of social support group meetings, creating a casual and safe space for those living with endometriosis to connect and educational workshops.

Most social meetings are open to bringing a loved one or support person with the objective of providing support and connection to family and carers as well as those whom they care for.

Educational meetings are delivered with medical and allied health professionals with the objective of educating members. Educational meetings are often filmed, and the content is made available publicly for educational purposes.

During the 2021-22 financial year, five educational workshops were delivered. The content from all five workshops was made publicly available in the 2021-22 financial year.

A team of 6 volunteers supported the delivery of support group events in financial year 2021-22.

Event Name	Speaker	Date	Engagement	Delivery	Available on YouTube?
<i>Advocating for a loved one</i>	Maxine Drake	7 August 2021	83%	In person	✓
<i>Non-surgical treatments of Endometriosis</i>	Bernadette McElhinney	2 October 2021	51%	Zoom	✓
<i>Social Christmas Catch-up</i>	N/A	4 December 2021	71%	In person	N/A
<i>Naturopathy & Endometriosis</i>	Samantha Smith	5 February 2022	40%	Zoom	✓
<i>Endometriosis & Medicinal Cannabis</i>	Mike Armour	14 May 2022	31%	Zoom	✓
<i>Endometriosis & Exercise Physiology</i>	Megan Fraser	4 June 2022	26%	Zoom	✓

Feedback from our members about our Support Group events in the 2021-2022 Financial Year:

- 55% of members would like an online mode of attendance to be available for all events
- *“Really interesting topics, love the in-person delivery”*
- *“They’re informative and inclusive”*
- *“They have helped me a lot, thank you”*



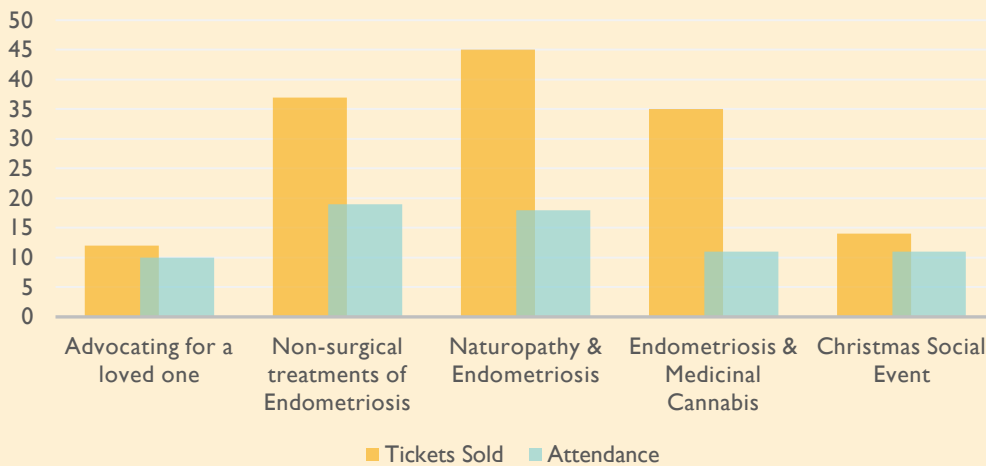
Support Group Events Data

A huge thank you to our dedicated Events Volunteers!



FIVE Educational Workshops

ONE social support meeting
71% engagement



4 / 5 events delivered online



ALL

educational workshops in 21/22 financial year published on EndometriosisWA's YouTube channel



Volunteer Training Opportunities

Throughout the 21/22 financial year, many of our volunteers at EndometriosisWA participated in various training opportunities, allowing them to expand and enhance their skillsets. We thank all training providers that provided opportunities to our volunteers.

Training Type	Provider	Date	Attendee
Social Media & Digital Marketing	ECU Executive Education	21/07/21	Monique Alva
Social Media Training	ConnectGroups	22/02/22	Monique Alva
Support Group Facilitation Training	ConnectGroups	21/10/21	Taylor Lynch Emma Atherton
Systemic Advocacy: How to influence decision-makers and change the world	ConnectGroups & Evolve Events and Training	22/01/22 22/02/22	Charmaine Galea Pipp Hamilton
Grant Writing Workshops	ConnectGroups	22/03/22	Charmaine Galea
Mental Health Capability: a workshop for non-mental health focused Peer Support Groups	ConnectGroups	22/04/22	Charmaine Galea
Key Issues of Volunteer Management and how to effectively recruit and retain volunteers	ConnectGroups and VolunteeringWA	27/04/22	Charmaine Galea
Growing and Remodelling Online and Face to Face Volunteering	ConnectGroups and VolunteeringWA	22/05/22	Charmaine Galea

AWARENESS & EDUCATION

Awareness and education are key pillars of Endometriosis Western Australia. We identify opportunities to lead, contribute to and/or fund community education and awareness programs, events, and activities to increase awareness and educate the community on endometriosis.

As outlined in our 'Timeline' (page 12), Endometriosis Western Australia coordinated and participated in a range of initiatives this financial year.

'SubieFest' – October 2021

In October 2021, Endometriosis Western Australia was chosen as the Beneficiary of 'SubieFest', an annual event showcasing WA's Subaru community with awards for "Best in Categories" & fund-raising for local charities. Throughout the day, our team raised awareness about endometriosis, provided information and brochures to interested attendees and had many great conversations about where to find support and information on endometriosis in Western Australia. President, Kiera Collier delivered a speech to the crowd about the work EndometriosisWA does. A total of \$15,000 was raised for EndometriosisWA, our largest donation to date. We would like to extend our sincere thanks to the organisers of SubieFest and everyone who attended that contributed to this donation. The funds raised will go a long way in ensuring our organisation can continue to run, provide support to those living with endometriosis and continue to advocate for improved services for endoWARRiors.



[9News Perth Interview](#) – November 2021

Support Group Member Christine Trimboli and Deputy President Akaiti James were interviewed by 9 News Perth about the on public health system wait times. We thank Christine for sharing her story and raising awareness of the impact that extended wait times have on people with endometriosis.

- *Ms Trimboli said she was shocked when her doctor told her surgery would be classified as a non-urgent, category three procedure. "I was thinking that it would be category one, the most urgent, because I am so sick," she said. Ms Trimboli said she was told it would be about a 10-month wait to get an initial appointment with a surgeon and then a further eight months before the surgery.*
- *Deputy president of Endometriosis Western Australia, Akaiti James, said waiting times for people with endometriosis were "cruel". Many people with endometriosis spent years trying to find out what was wrong with them, and elective surgery waiting times only exacerbated the problem, Ms James*

said. "With endometriosis, there is a 6.5-year delay in diagnosis, so that is a long time to be going to a doctor and to be having pain and not being validated." Without an official diagnosis, people were unable to access services they may need to help treat the symptoms of the condition, Ms James said.

Advocacy for RANZCOG National Guideline Changes

In March 2022, the RANZCOG Guidelines for Endometriosis came under scrutiny from the endometriosis community throughout Australia. To advocate on behalf of members, EndometriosisWA resolved to send a public letter to RANZCOG addressing the concerns of the community. Members were given a month to provide feedback, which was collated along with a review of international guidelines and peer reviewed literature. Please find a copy of the letter in Appendix 1. At the time of which this report was written, Endometriosis Western Australia has not received a response to the letter, however we will continue to follow up with RANZCOG.

Advocacy for tertiary health services

During the past year, EndometriosisWA advocated for colorectal services to be provided at King Edward Memorial Hospital (KEMH) for patients undergoing complex surgeries for endometriosis with bowel involvement. Members who had been affected by the lack of colorectal support at KEMH volunteered to share their experiences of how lack of access to services impacted their daily lives. This culminated in a formal letter that was sent to both State and Federal Governments with a positive response received from the office of the Western Australian Minister for Health, Hon Amber-Jade Sanderson BA MLA.

As a result, EndometriosisWA are pleased to announce that colorectal support has commenced with the endoscopy service through the loan of colorectal surgeons from Sir Charles Gairdner Hospital, and surgeries are now being scheduled as of August 2022.

Perth Networking Club Presentation – March 2022

In March, Endometriosis Western Australia's Secretary, Tegan Phillips delivered an outstanding speech at Perth Networking Club event for International Women's Day.

Tegan shed light on the impact of endometriosis on an individual's physical, emotional, financial, and social wellbeing, shared personal anecdotes and spoke about the work we do at EndometriosisWA.

It was excellent to see this spark conversation about endometriosis in the crowd, especially during endometriosis awareness month! A big thank you to Perth Networking Club for running this event and choosing EndometriosisWA as one of your beneficiaries this month.



EndoZone Project

EndoZone is an evidence-based website co-created with people affected by endometriosis. The platform is funded by the Australian Government Department of Health and Jean Hailes for Women's Health, and was developed by researchers, health experts, Australia's endometriosis associations, and consumers.

EndoZone provides evidence-based education and self-management strategies for endometriosis. It includes a clinician section for doctors and healthcare providers and a research section with latest research studies on endometriosis.

EndometriosisWA were invited to contribute to the development of the platform. EndometriosisWA shared EndoZone's research and consultation opportunities with our members to ensure Western Australians with endometriosis had the opportunity to provide feedback and contribute to the platform.

EndometriosisWA also wrote articles for the platform for supporters like parents, partners, teachers and employers to better support those affected by this condition. Thank you to Board Member, Dr Katya Fleming, Treasurer Rebecca Kale and Secretary Tegan Phillips for their contributions to the EndoZone platform.

Guides for helping someone you know with endo



Advice for teachers



Advice for partners



Advice for parents



Advice for bosses

In April, EndometriosisWA President, Kiera Collier attended the launch of the EndoZone platform in Adelaide. This was a wonderful opportunity to meet with the EndoZone team, researchers and developers of the platform, and other ACE organisations to celebrate the launch of the platform.



We commend the work of the EndoZone team in developing this resource, and we look forward to the continued development of the platform. EndoWARRiORS can provide feedback on the platform via endozone.com.au.

Social media and digital communications

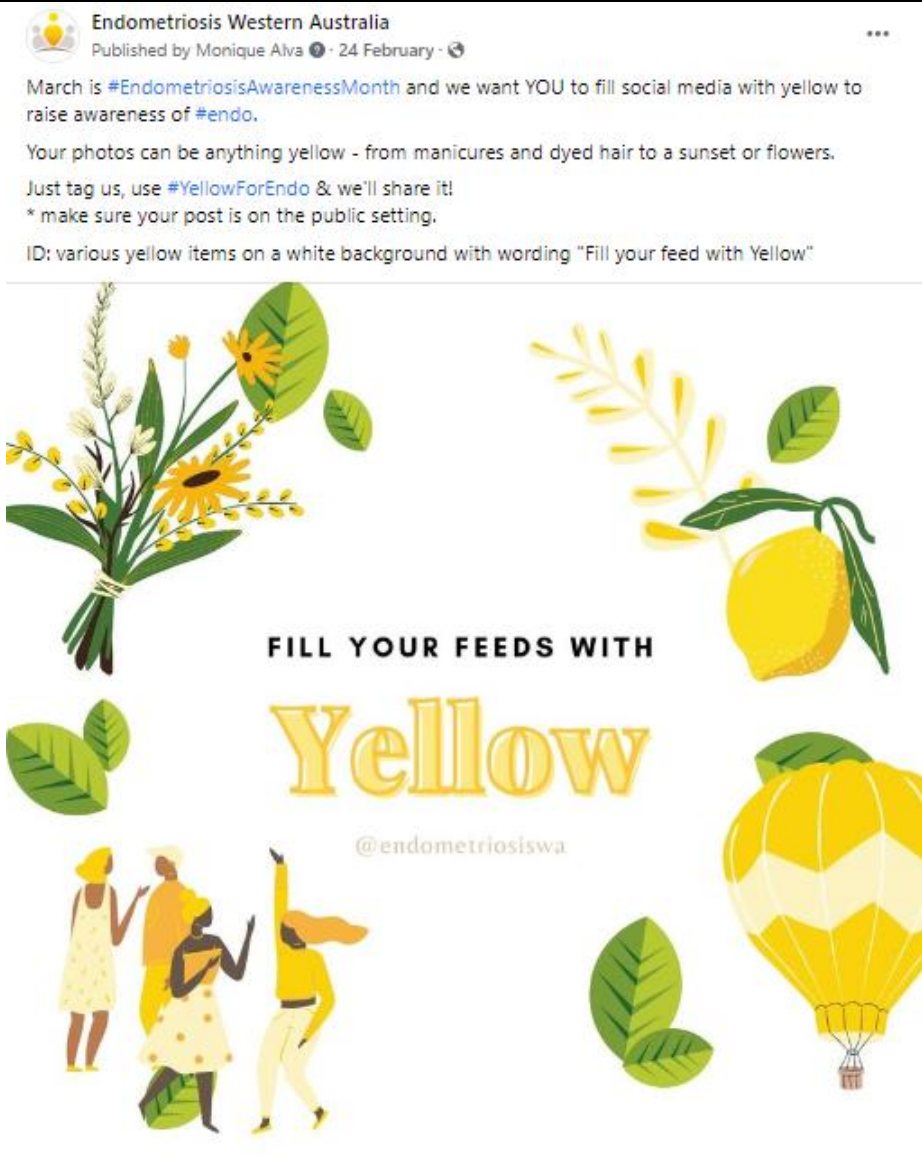
Newsletter Statistics

- 7 Newsletters written and delivered in the 2021-2022 Financial Year
- Total of 551 current subscribers
- Increase of 35 subscribers since 2020-2021 financial year

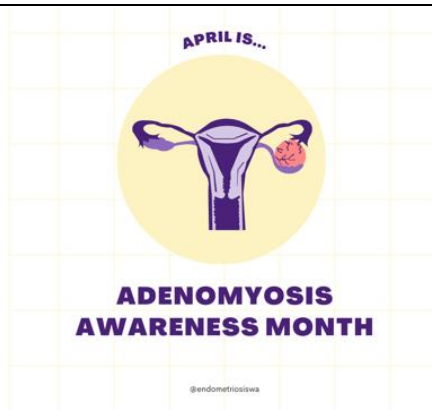
Digital campaigns

EndometriosisWA's education and awareness campaigns aim to educate and support the endometriosis community by providing public infographics with useful, evidenced-based information.

Some examples of educational campaigns delivered in the 2021-2022 financial year can be found below. Please visit Endometriosis Western Australia's social media accounts to view all digital campaigns.

<p>March Endometriosis Awareness Month Campaign #fillyourfeedswith yellow</p>	 <p>Endometriosis Western Australia Published by Monique Alva · 24 February · 🌐</p> <p>March is #EndometriosisAwarenessMonth and we want YOU to fill social media with yellow to raise awareness of #Endo.</p> <p>Your photos can be anything yellow - from manicures and dyed hair to a sunset or flowers.</p> <p>Just tag us, use #YellowForEndo & we'll share it! * make sure your post is on the public setting.</p> <p>ID: various yellow items on a white background with wording "Fill your feed with Yellow"</p> <p>FILL YOUR FEEDS WITH Yellow @endometriosiswa</p>
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Adenomyosis Awareness Month
April 2022



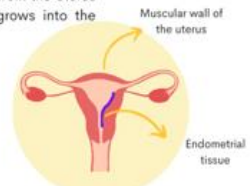
WHAT IS ADENOMYOSIS?

Adenomyosis occurs when tissue from the uterus (known as **endometrial tissue**) grows into the **muscular wall** of the uterus.

Endometrial tissue normally gets **thicker, breaks down,** and bleeds (that's why we menstruate).

But because this occurs in the muscular wall instead of its normal location, and displaced tissue continues to thicken, break down and bleed,

the uterus becomes **enlarged-** resulting in **painful periods.**



ALLIED HEALTH SERVICES THAT MAY HELP

Pelvic Physiotherapy for the management of pelvic pain associated with adenomyosis



Psychology to assist with the emotional and mental burden of adenomyosis, and to prevent triggering factors such as anxiety and lifestyle choices

Massage therapy to for abdominal wall and pelvic pain, as well as locating muscular trigger points to aid in the management of uterine, bladder, rectal, and digestive organ discomfort.



@endometriosiswa

Top 3 tips
July 2021-Present

TOP 3 TIPS- AUGUST 2022 SUPPORT GROUP

Endometriosis & Nutrition.

According to Dietician Sarah Viney



1. Focus on increasing colourful fruit and veg. Aim for 3 different colours.

2. Add more fibre to your diet. Fibre improves gut health and low fibre diets can lead to constipation.

3. Remember that dietary changes are not a quick fix; they take time.

TOP 3 TIPS- JANUARY 2022 SUPPORT GROUP

Naturopathy & Endo.

According to Naturopath, Samantha Smith



1. A gluten free diet can help pain and inflammation

2. Attempt to increase diversity in your microbiota. Partially hydrolysed guar gum can help!

3. Consider dietary sources of Omega 3 to help with pain and inflammation.

@endometriosiswa

Feedback from our members about awareness and social media campaigns in the 2021-2022 Financial Year:

- "Keep doing the great work you are currently doing"
- "Would be great to have booklets with support advice for friends and family to support someone living with endo"
- "More of them! They are great. Maybe promote containers for change more?"
- "Larger scale awareness campaigns that get the community involved e.g. challenges could be good"
- "Would be good to see more storied"
- "Brilliant, keep up the great work. Suggestion of making options available for the public that don't have access to social media"
- "Would like educational campaigns targeted at employers"

Marketing and Branding Evolution

Over the past couple of years, Endometriosis Perth Sisterhood of Support rebranded to Endometriosis Western Australia Incorporated and EndometriosisWA's support group changed its name to 'Endometriosis Western Australia Warriors' to reflect our core value of 'community', demonstrating unity, equality and equity. This financial year, this past financial year, the organisation has continued to update its marketing and branding to present captivating, informative, relatable and inclusive materials to the endometriosis community. This resulted in a 'refresh' of our social media graphics to create a cohesive brand across our platforms and a revision to our brochure.

Thank you to our Social Media Team, Monique Alva and Katia Fernandes for their hard work on this transition.



We extend our thanks to Des Hameister for volunteering his time to EndometriosisWA to redesign our brochure.



What is endometriosis?

Endometriosis is a common disease where tissue similar to the endometrium (lining of the uterus) is found growing in other parts of the body.

The tissue may break down and bleed each month, especially during menstruation (periods) and can lead to inflammation, scarring and adhesions.

Scientists do not know how and why endometriosis forms, but risk factors may include a family history of endometriosis, low birth weight, early age of first period, and long and heavy periods.

Symptoms

Endometriosis symptoms vary between individuals and do not always correlate with the severity of the disease. Symptoms of endometriosis may include:

- pain during periods, sex or ovulation
- chronic pain in the pelvis, lower back and legs
- fatigue and/or nausea
- bowel and bladder pain when going to the toilet
- constipation and/or diarrhoea
- difficulty falling pregnant (infertility)
- heavy or irregular bleeding.

Severe period pain is not normal. If the pain is so severe that you are missing school, work and other activities, please speak to your doctor.



Diagnosis

Endometriosis is most frequently diagnosed during laparoscopic surgery, normally to investigate pelvic pain or fertility concerns. Occasionally it will be identified during surgery for other conditions. The tissue is removed and sent to pathology for analysis under a microscope to confirm the diagnosis.

Treatment

There is currently no cure for endometriosis. Treatments involve surgery and/or medications such as pain killers and hormone therapies to manage symptoms. Modifying your lifestyle, such as dietary changes and improving sleep, may also have a positive effect on symptoms.

Reference: www.eshre.eu/Guidelines-and-Legal/Guidelines/Endometriosis-guideline.aspx
The information provided in this brochure is not professional medical advice. Always seek the guidance of a qualified health professional regarding your specific circumstances.

Join our online support group

Endometriosis Western Australia WArriors is our online support group for people with endometriosis in WA.

Our mission is to provide members with access to a strong peer support network that promotes member empowerment and community education.

EndoWArriors members receive:

- Access to online peer support
- Free bi-monthly newsletter
- Invites to free bi-monthly events

To request to join the endoWArriors, you must:

- be born or reside in Western Australia
- have or currently be seeking a diagnosis of endometriosis or adenomyosis
- be joining for individual support purposes
- agree to adhere to the group guidelines.

Scan the QR code below to find out more

Or visit endometriosiswa.org.au for information on how to subscribe to our newsletter and event alerts.



EndometriosisWA's website, endometriosiswa.org.au is currently under development, thanks to a ConnectGroups Give It Forward grant received in June 2021. The grant has supported the outsourcing, design and build of a professional website, including simplifying content for good flow and professional feel, reviewing content and layout to create a website that accurately reflects Endometriosis Western Australia. The new website is being designed on a user-friendly platform ensuring maintenance is simple, sustainable and can be completed internally.

RESEARCH

Endometriosis Western Australia support and promote research into the causes, diagnosis, prevention and management of endometriosis.

ENDORIGINS endometriosis tissue biobanking project

Background: Endometriosis Western Australia is proud to support the ENDORIGINS endometriosis tissue biobanking project in conjunction with University of Western Australia, the Fiona Wood Foundation and King Edward Memorial Hospital. ENDORIGINS is a 5-year study which aims to understand the origins of endometriosis through collection of biospecimens and clinical data. Through setting up this project, we aim to increase the amount of research into endometriosis locally in Western Australia.

2021-2022 Progress Summary: The biobank was significantly impacted during the COVID-19 pandemic due to the cancellation of surgeries. The first participant was recorded in October 2021 and collection was resumed in July 2022. In addition, the research team continues to grow and has acquired two more PhD candidates and a clinical Fellow. The plans for the following year include continuing participant enrolment and development of vacation research and Honours projects.

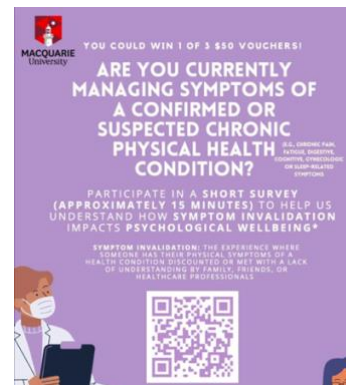
Research engagement opportunities promoted

EndometriosisWA share research opportunities with our members and the wider community through our digital communications. Research must have ethics approval to be shared.

“[Macquarie University](#) researchers are currently conducting a brief survey to understand the experience of symptom invalidation (i.e., the dismissal or rejection of health symptoms by doctors, family or friends) on Australian adults living with chronic physical health conditions.

Ultimately, the goal of this study is to understand how they can help train members of our community (e.g., doctors, family and friends) to be able to support individuals with chronic physical health conditions better.”

“Researchers from Perth-based biomarker company Proteomics International are collaborating with The University of Melbourne and The Royal Women's Hospital to develop a simple blood test for endometriosis. Proteomics International will use the largest and most in-depth endometriosis database and tissue bank in Australia with more than 900 women with endometriosis to validate the panel of biomarkers. They are looking for women without endometriosis to get involved in this research project as a healthy comparison group. It is important that they get input from friends and family who do not have endometriosis but would like to support the research on endometriosis. They are seeking healthy volunteer women aged 18 – 50 with regular menstrual cycles and no endometriosis-related gynaecological symptoms. The study will involve a blood sample taken by a qualified phlebotomist. You will be invited to complete a pre-screening questionnaire to ensure your suitability for this study and will receive a reimbursement fee once you qualify and complete the study.”



Proteomics International

HEALTHY VOLUNTEERS NEEDED

Researchers from Proteomics International are seeking healthy female volunteers for a research project to help develop a simple method to improve the diagnosis of endometriosis by using blood.

We are recruiting healthy volunteers for comparative purpose in this research project.

Open to women who:

- Are aged 18-50, with normal menstrual cycles
- No endometriosis-related gynecological symptoms

The study involves:

- A blood sample in a single timepoint will be collected from qualified phlebotomist.

You will be invited to complete an online or telephone questionnaire to ensure your suitability for this study. Once you qualify and complete the study, you will receive a reimbursement fee. Dates & times for volunteers are flexible.

For more information, please contact Linear Clinical Research by calling 1300 546 327 (1300LINEAR) or email contactus@linear.org.au

"@uni_roehampton and @endophdstudent Jodie Hughes are studying the effects of different factors on Endometriosis care.

We would appreciate it if you can spare 10 – 15 minutes of your time to take part in this survey open to all people with Endometriosis.

The answers to this survey will assist in determining best care practices."

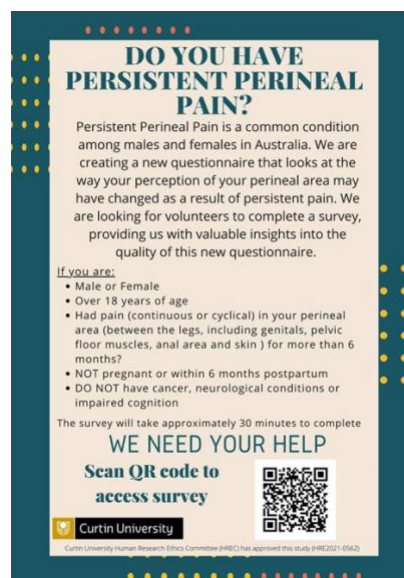


"If you have persistent #perineal pain then we need you!

Researchers at @curtinuniversity need your help to test a new questionnaire measuring how people with persistent perineal pain perceive this area of their body.

Your input will help to refine this new questionnaire, which will ultimately help clinicians better understand how body perception is altered in people with persistent perineal pain, and hence improve treatment outcomes.

Please click on the link in our bio to complete this survey, which is completely anonymous and will take approximately 30 minutes of your time."

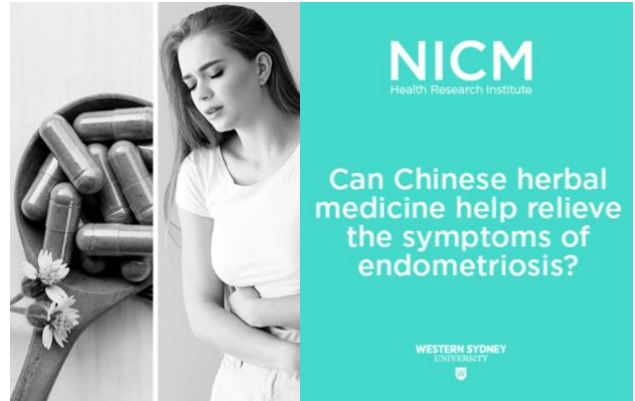


"A PhD student from Stellenbosch University is recruiting for a study that is exploring the experience of transgender and non-binary people living with endometriosis.

As part of this study you would need to take part in 3 online interviews and complete a diary (brief daily reflections on your experience of endo). Confidentiality will be maintained and the use of pseudonyms will be used to protect participant's identity."

RECRUITMENT FOR RESEARCH STUDY:	We are looking for transgender and non-binary people who are living with endometriosis to take part in a research study.
TRANSGENDER AND NON-BINARY PEOPLE'S EXPERIENCE OF LIVING WITH ENDOMETRIOSIS	<ul style="list-style-type: none"> - Do you identify as transgender and / or as non-binary? - Have you been diagnosed or have suspected endometriosis? - Are you eighteen years or older?
This research study is conducted by Stellenbosch University in South Africa.	Volunteers can come from anywhere in the world and must be able to speak English.
Researcher: Cheryl Eder cje@live.co.za Supervisor: Dr Rizwana Roomaney rzwanao@sun.ac.za	If you are interested in being a participant or wanting to learn more, please contact Cheryl Eder You can email: cje@live.co.za or phone or whatsapp on: +36707242313

“Chinese Herbal Medicine for Endometriosis – Clinical trial Researchers from Western Sydney University and the University of New South Wales, led by Dr Mike Armour, are currently running a clinical trial on the effectiveness of a modification of a traditional Chinese medicine formula (Gynoclear) on the symptoms of endometriosis. This trial is open to people Australia wide and will involve having two blood tests, one at the start and one at the end of the trial, filling in online pain and symptom diaries, and taking six capsules per day for three months. Apart from the two blood tests the entire trial is online, no in person visits are needed. This is a placebo-controlled trial so there is a 50% chance you will get a placebo or the active treatment, however all people in the placebo group will receive three months’ supply of Gynoclear at the end of the trial if its shown to be effective.”



OVERALL FEEDBACK 2021-2022 ANNUAL SURVEY

General Feedback from our Members

- *“Good to know your there, if and when needed for information and support.”*
- *“Appreciate everything that’s been done and as a warrior it’s really reflecting on how I think about endometriosis to what I used to think about it”*
- *“Other than the Facebook group which is a great community I’m unsure what else you offer and what funds are used for”*
- *“I don’t know how I could’ve got through my diagnosis journey without the support and education that the Facebook group chat provided me”*
- *“Needs a lot of work, needs more attention and consistency!”*
- *“This has been a great resource, being able to educate myself on my condition and realising I’m not alone with the issues that arise from this horrible disease.”*
- *“An organisation that provides invaluable support to people with endometriosis”*

What is most important to our members?

In order of priority:

1. Endometriosis awareness and education in Western Australia
2. Peer support online
3. Endometriosis Research in Western Australia
4. Peer support in person

What would our members like to see more of?

In order of priority:

1. Presence of our organisation in the community
2. Educational materials
3. Educational workshops provided to members for free
4. Promotion and awareness of endometriosis via our social media accounts
5. Social Media awareness campaigns that members can participate in
6. Educational videos
7. Member stories on our webpage
8. Fundraising campaigns and opportunities
9. Other (nil suggested)

Endometriosis Western Australia Inc has...

Statement	Average (Stars/5)
<i>... provided me with access to high quality information.</i>	4.5 Stars
<i>... provided me with care and support.</i>	4.3 Stars
<i>... provided me with educational resources that have proved beneficial to wellbeing.</i>	4.5 Stars
<i>... increased my self-confidence to self-advocate.</i>	4.6 Stars
<i>... helped me feel understood, connected and supported.</i>	4.4 Stars

SECTION 5 – FINANCIAL STATEMENTS

Assets		
Total Assets	\$0	\$0
Liabilities		
Total Liabilities	\$0	\$0
Net Assets		
Income		
Revenue and grants from government		
Donations received		
Tax Deductible Donations (Non-public)		\$20.00
Donations (Public collections)		\$21,737.03
Non-tax deductible gifts		\$142.20

Fundraising - Contributions		
Contributions (Members)		\$370.00
Operating Activities		
Sales of goods		\$446.00
Fees and Charges - Unrestricted		\$5,724.20
Other Income		
Total Income		\$28,439.43
Cost of Goods Sold		
Purchases	\$468.00	
Cost of Goods Sold	\$468.00	
Expenses		
Advertising & Promotion	\$198.00	
Assets Purchased <\$5,000	\$73.00	
Bank Charges	\$3.33	
Board/Governance Expenses	\$77.00	
Client Support Services	\$62.00	
Computer Expenses	\$549.61	
Depreciation		
Donations Paid	\$5,000.00	
Insurance		
Insurance - General	\$761.00	
Meeting Expenses	\$47.00	
Membership Fees Paid	\$55.00	
Printing & Stationery	\$29.00	\$8.49
Sundry Expenses	\$49.00	
Telephone & Fax Charges & Internet	\$243.00	
Total Expenses	\$7,608.28	
Net Profit		\$20,831.15

NOTES TO THE FINANCIAL STATEMENTS

Corporate information

Endometriosis Western Australia Incorporated is:

- Endorsed by the Australian Taxation Office (ATO) as a deductible gift recipient (DGR) by Item 1 of the table in section 30-15 of the *Income Tax Assessment Act 1997* (Cth);
- Endorsed by the ATO to access the tax concessions for goods and services tax (GST), income tax exemption and fringe benefits tax (FBT) exemption.

Members of the Board, event and social media volunteers act in an honorary capacity and receive no compensation for their services.

Basis of preparation

Endometriosis Western Australia Incorporated has adopted the [National Standard Chart of Accounts](#) (NSCOA) as a guide for reporting financial information. The report is presented in Australian dollars.

- Grant income arising from an agreement is fully recognised when the performance obligations are satisfied.
- All expenditure is accounted for on an accrual basis and classified under the relevant headings on a gross basis. Some expenses are invoiced in United States dollars and have been converted using the prevailing exchange rate at the date of the transaction.
- Although not formally adopted, we have also sought to align with the Voluntary Code of Practice for Public Fundraising in Western Australia where relevant.

Statutory financial reporting requirements

At the date of this report, Endometriosis Western Australia Incorporated was classified as a small charity size with total annual revenue of less than \$250,000 per annum. Endometriosis Western Australia Incorporated is therefore not required to prepare General Purpose Financial Reports (GPFR) or Special Purpose Financial Reports (SPFR) which comply with the Australian accounting standards issued by the Australian Accounting Standards Board (AASB).

A signed declaration by Responsible Persons confirming Endometriosis Western Australia Incorporated can pay its debts as and when they fall due is also not required at the date of this report.

The ACNC legislation requires Endometriosis Western Australia Incorporated to prepare and lodge its Annual Information Statement (AIS) within six months from the financial year ending 30 June 2022 (i.e. by 31 December 2022) but does not require financial reports to be externally reviewed, audited or submitted with the ACNC. Where possible, this report aligns with the requirements of the AIS to disclose non-financial and financial information.

SECTION 6 – OTHER IMPORTANT INFORMATION

ACKNOWLEDGEMENTS AND THANK YOU

We would like to thank all our donors and supporters who provided financial and in-kind contributions to us during the 2021-2022 financial year.

Corporate and community partners

[Australian Coalition for Endometriosis](#)
[ConnectGroups](#)
[World Endometriosis Organisation](#)
[Volunteering WA](#)

HOW YOU CAN HELP

Become a member, corporate sponsor or volunteer your time

Email info@endometriosisWA.org.au to register your interest.

Alternatively, find us on [SEEK Volunteer](#).

Make a donation or leave a bequest

Account name: Endometriosis Western Australia Incorporated
BSB: 036-067
Account number: 662126
Description: Your surname or company name

Please email a copy of the transfer receipt to accounts@endometriosisWA.org.au.

Support an event or fundraising activity

<https://www.mycause.com.au/charity/38577/EndometriosisWesternAustralia>

CONTACT US

PO Box 711 Cloverdale WA 6985

Website: endometriosisWA.org.au

Email: info@endometriosisWA.org.au



20th June 2022

Dr Benjamin Bopp
President
The Royal Australian and New Zealand College of Obstetrics and Gynaecologists
Sent via email: ranzocg@ranzocg.edu.au

Dear Dr Benjamin Bopp,

Re: Call for revision of the RANZCOG Endometriosis Clinical Guidelines

Endometriosis Western Australia is a not-for-profit support and advocacy organisation that represents the interests of those living with endometriosis in Western Australia, supporting more than 4,500 members through our online support group alone. We acknowledge and appreciate the efforts of RANZCOG members in creating our existing endometriosis clinical guidelines. However, we believe the current guidelines fail to address the needs of the endometriosis community for many reasons, including recent advancements in research, a lack of guidance for pain management and minimal community consultation during their creation.

Our organisation recently sought feedback from the community about their concerns with the guidelines in the current form, and what they would like to see in the next iteration. The following is a summary of their concerns and recommendations.


1. Access to appropriate surgical intervention

Concerns regarding the current level of access to surgery and the type of surgery provided was a primary concern of all our members. We see this reflected in discussions that take place on social media and in our private online support group. The specific concerns provided include the following:

1.1 Access to excision

All our members were concerned about the current level of access to specialised excision surgery, and the use of ablation to treat deeply infiltrative endometriosis. Some people shared personal stories of having received sometimes multiple ablative procedures with no relief of symptoms, only to learn about excision techniques years later and undergo repeat surgery with far better outcomes. The primary demand from the community is that excision surgery be offered to all people with endometriosis. This is especially important for people with deeply infiltrative endometriosis, who are not often provided with pre-operative assessments including specialised ultrasound or MRI imaging, and so are not appropriately triaged to the appropriate advanced laparoscopic surgeon. The 2022 ESHRE guidelines support an excision focused approach (section II.3.b),

Recommendation (25)

When surgery is performed, clinicians may consider excision instead of ablation of endometriosis to reduce endometriosis-associated pain. 

further clarified by stating “The excisional approach is likely to be more suitable for deep endometriosis lesions, as it is impossible to know if the entire lesion is destroyed with ablative techniques.”¹

1.2 Repeated and multiple surgeries

Related to the above concerns, many members were distressed at the number of surgeries performed by less experienced surgeons before they were able to access an excision expert. Some members report 6 months or less between surgical interventions. Members postulate this is due to an inability to recognise endometriotic lesions, the use of ablative techniques, or generally substandard treatment. They would like people to receive their first surgical intervention from trained endometriosis experts.

1.3 Guidelines for surgically complex cases

The current guidelines are sparse on specific recommendations for involvement of pelvic organs such as the ovaries or rectum, or on surgical techniques for endometriosis outside the pelvis. The ESHRE guidelines contain extensive information on ovarian endometriosis (II.3.e) and bowel endometriosis (II.3.f.1), and discuss the signs and symptoms suggestive of extra-pelvic disease (VII.1.b) that would necessitate a multidisciplinary approach.¹ Our members are concerned that only their pelvic endometriosis is being detected and treated and believe the guidelines must address how this can be diagnosed.

1.4 The use of adjunct hormonal therapies

Our members believe the use of medication, particularly hormonal medication, is too heavily relied upon as a way to avoid or unnecessarily delay surgery. Some report that surgery wasn't offered as an option unless they agreed to a trial, with concerns about coercion. Some people decide they would like surgery before or during their initial consult and are still placed on hormonal therapy, which is not supported in the ESHRE guidelines (II.4.a),¹

Recommendation (35)

It is not recommended to prescribe preoperative hormone treatment to improve the immediate outcome of surgery for pain in women with endometriosis.



or the NICE decision aid “Hormone treatment for endometriosis symptoms – what are my options?”²

This decision aid covers hormonal contraceptives because they are the first kind of treatment for endometriosis symptoms most women are asked to think about trying, in addition to pain-killers. **You do not have to try hormone treatment.**

Our members would like more autonomy with regards to their treatment options and a more well-rounded education from clinicians on the reasons and risks in prescribing this medication from the outset.

2. Improving early diagnosis

The diagnostic delay is well recognised, an experience that is reflected in the stories of our members. This was variably due to delay at the general practitioner level, to lack of recognition in emergency departments, and due to gynaecologists in rural and remote areas being inexperienced in the recognition of the varied presentations of endometriosis. Our members identified two areas they would like to see addressed in the new guidelines to help reduce this delay.

2.1 Community specific guidelines

Most of our members report the diagnostic delay occurring at the primary care level, or between primary and specialist care. Our rural members report underdiagnosis and misdiagnosis by specialist services in rural areas. This includes both a lack of knowledge about endometriosis, a lack of clarity about how and where to refer patients, and what the most appropriate investigations are pending a specialist appointment. They would like to see guidelines that comprehensively address the symptoms such as those in the ESHRE guidelines (I.1),¹

Recommendation (1)

The GDG recommends that clinicians should consider the diagnosis of endometriosis in individuals presenting with the following cyclical and non-cyclical signs and symptoms: dysmenorrhea, deep dyspareunia, dysuria, dyschezia, painful rectal bleeding or haematuria, shoulder tip pain, catamenial pneumothorax, cyclical cough/haemoptysis/chest pain, cyclical scar swelling and pain, fatigue, and infertility.

GPP

and that address that detection can be challenging, such as in the NICE Guidelines (1.5).³

Do not exclude the possibility of endometriosis if the abdominal or pelvic examination, ultrasound or MRI are normal.

A clear guide to aid development of streamlined local referral pathways would also be beneficial, particularly highlighting signs that are suggestive of deeply infiltrative endometriosis that would require the attention of a specialist centre. This could also specifically address rural areas, including early recognition of complex cases and cases finding no relief from local management, that may require a referral to subspecialist centres.

2.2 Increased recognition of adolescents

Many our members report having symptoms begin in adolescence, some as early as menarche. Despite this, many were told that they were too young to have developed endometriosis, or that they are too young for surgery. This is contrary to evidence, with ESHRE recommending (V.1.c),¹

Recommendation (72)

In adolescents, clinicians should take a careful history and consider the following symptoms as suggestive of the presence of endometriosis:

- chronic or acyclical pelvic pain, particularly combined with nausea, dysmenorrhea, dyschezia, dysuria, dyspareunia
- cyclical pelvic pain.

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and (V.2.b).

Recommendations (82-83)

In adolescents with endometriosis, clinicians may consider surgical removal of endometriosis lesions to manage endometriosis-related symptoms. However, symptom recurrence rates may be considerable, especially when surgery is not followed by hormone treatment.

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The GDG recommends that if surgical treatment is indicated in adolescents with endometriosis, it should be performed laparoscopically by an experienced surgeon, and, if possible, complete laparoscopic removal of all present endometriosis should be performed.

GPP

Members would like adolescents to be specifically addressed to prevent this early diagnostic delay.

3. The use of gender inclusive language

Our members and our organisation value, welcome, and respect our trans and non-binary peers, and recognise their additional barriers to seeking gender appropriate care and support. At an organisational level this has been reflected in the name of our support group changing from “Endometriosis Perth Sisterhood of Support” to “Endometriosis Western Australia WArriors”. We also avoid the use of gendered language in all our official documentation and communications. Our members reflected this value in their feedback, with two specific recommendations.

3.1 Gender neutral language

To date, we are not aware of any guidelines who have incorporated this change of language to recognise this disease affects more than women. This is despite both calls from the community to recognise these people (for example, reported by [Endo Found](#)⁴ and the [CBC](#)⁵). It is recognised that endometriosis is historically a gynaecological “women’s” issue, but with our increasing awareness of gender diversity this is no longer the case. There are multiple ways this can be addressed, with examples including replacing “women” with “people”, or clarifying “women and a number of trans and non-binary individuals”

3.2 Moving away from describing endometriosis as a menstrual disorder

Endometriosis is a complex disease, and while it is acknowledged many people living with disease experience cyclical symptoms related to menstruation, this is certainly not the case for all people. Chronic pain unrelated to the stage of the menstrual cycle is frequently reported our members. Symptoms persisting despite treatment that suppresses menstruation is common. The disease is so enigmatic that our members highlighted their awareness of the disease being found in people assigned male at birth, discussed at [Extrapelvic Not Rare](#).⁶ While we understand in depth discussion may not be relevant for a gynaecology focused guideline, the members have asked for it to be acknowledged.

4. The association with ovarian cancer

Our members were very concerned that the correlation between endometriosis and ovarian cancer was largely dismissed in the Australian guidelines without more extensive examination of the literature.

There is a significant body of research examining the potential links, and while research quality may be inconsistent, our members do not want it ignored. The new ESHRE guidelines have the benefit of additional years of research to comment on, and have the following recommendations (multiple recommendations from section X. Endometriosis and Cancer).¹

Recommendation (104)

Clinicians should inform women with endometriosis requesting information on their risk of developing cancer that endometriosis is not associated with a significantly higher risk of cancer overall. Although endometriosis is associated with a higher risk of ovarian, breast, and thyroid cancers in particular, the increase in absolute risk compared with women in the general population is low.

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Recommendations (107-108)

In women with endometriosis, clinicians should not systematically perform cancer screening beyond the existing population-based cancer screening guidelines.

⊕⊕○○

Clinicians can consider cancer screening according to local guidelines in individual patients that have additional risk factors, e.g., strong family history, specific germline mutations.

GPP

Recommendation (109)

Clinicians should be aware that there is epidemiological data, mostly on ovarian endometriosis, showing that complete excision of visible endometriosis may reduce the risk of ovarian cancer. The potential benefits should be weighed against the risks of surgery (morbidity, pain, and ovarian reserve).

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Recommendations published in [The Lancet](#) in 2017 also summarise the available information in a patient focused format that recognise the link.⁷



Panel: Key messages for clinicians addressing the concerns of women with endometriosis about ovarian cancer risk

Am I going to get ovarian cancer?

- Most women with endometriosis never develop ovarian cancer. Although several studies report an increased ovarian cancer risk, evidence suggests that the overall likelihood of you developing ovarian cancer is low. Thus, you should be aware of, but not worried about, the effect of endometriosis on your ovarian cancer risk.
- Although 1.3% of women in the general female population will develop ovarian cancer in their lifetime, this proportion is still less than 2% in women with endometriosis. Thus, although the risk is increased, your lifetime risk is low and is not substantially different from that in women without endometriosis. To put the risk in perspective, according to recent estimates, 39% of women who inherit a harmful BRCA1 mutation and 11–17% who inherit a harmful BRCA2 mutation—the rare genes that predispose to breast cancer—will develop ovarian cancer by 70 years of age. Furthermore, as a woman in the general population, your risks of breast (12%), lung (6%), and bowel (4%) cancers are still higher than your risk of developing ovarian cancer.
- Certain types of ovarian cancer are more commonly associated with a history of endometriosis. These endometriosis-associated cancers tend to be detected at an earlier stage and have a better prognosis than other types of ovarian cancer.

What can I do to lower my cancer risk?

- No clear evidence exists that transvaginal ultrasound or serum CA-125 measurements can detect ovarian cancers early or that risk-reducing surgery to remove the ovaries can save lives. Generally, to improve health and reduce the risk of cancer, try to have a balanced diet with low intake of alcohol, exercise regularly, maintain a healthy weight, and do not smoke.

Members are also aware of the genetic correlation between endometriosis and some ovarian cancers including endometrioid ovarian cancer, clear cell ovarian cancer, and potentially high grade serous ovarian cancer, which was recently described in the literature by Queensland researchers [Dr Sally Mortlock et al.](#)⁸

5. Recognition of common associated conditions

Most of our members who provided feedback describe having comorbidities as a result of their experiences living with endometriosis. They would like to see these acknowledged more in the new guidelines.

5.1 Pain

Chronic pain is a well-recognised comorbidity of endometriosis. Our members would like to see a more detailed discussion around the pain associated with endometriosis, and recommendations for pain management that are tailored to specific presentations. The ESHRE guidelines discuss this extensively in Section II.1 to II.6.¹

5.2 Mental illness

Mental illness and negative effects on emotional wellbeing are a well described consequence of living with endometriosis. This is described in multiple sections of the ESHRE guidelines, including in the Introduction and as a focus of long-term monitoring. Mental health is briefly mentioned in the NICE guidelines when discussing lifestyle interventions, with two further mentions of emotional wellbeing. The current RANZCOG guidelines mention this aspect of living with the disease only briefly when discussing the provision of information and support, and in the context of delayed diagnosis/misdiagnosis. A revised guideline would likely benefit from a greater focus on the risk of negative mental impacts not only at the time of diagnosis, but as a consequence of living with chronic illness.

5.3 Permanent disability

While most of our members report some degree of reduced function due to their symptoms, some members report profound disability due to unmanageable pain, the effects on other organ systems due to deeply infiltrative or extra pelvic endometriosis, or the associated mental illness. This is something that could be recognised in new guidelines.

6. The use of GNRH agonists i.e. Zoladex

Our members report concerns about the use of GNRH agonists given the severe side effects. Feedback varied from concerns about the use prior to confirmation of diagnosis, concerns about the long-term effects of prolonged use beyond 3-6 months, to dissatisfaction with it being offered as a treatment option at all. They would like a review of the use of these medications, better counselling of the risk and benefit for people offered this therapy particularly without a confirmed diagnosis, and clearer discussion of duration.

Other recommendations

Our members also had several recommendations on actions that RANZCOG could propose and work toward in conjunction with other organisations. These included:

1. Make “endometriosis specialist” a protected term.

Many members were concerned that practitioners from surgeons to CAM professionals can advertise themselves as specialised in endometriosis, without any specific training. They would like a way to be reassured they are choosing the right team.

2. Increase the number of expert surgeons.

Our members would like to see more training positions for advanced laparoscopic surgeons, with a focus on effectively detecting and treating endometriosis, and see more of them in publicly accessible positions.

3. Consider making endometriosis a subspecialty.

Some members report that despite being excellent surgeons, their chosen specialist did not have a good understanding of how to treat endometriosis. It was suggested that endometriosis may be complex enough to require its own subspecialisation.

4. Improve access to treatment through Medicare and the PBS.

Some recommended treatments, such as pelvic floor physiotherapy and Visanne, are prohibitively expensive for people whose income is affected by this disease. Increased rebates would help ease this burden.

5. Increase awareness in general practice and in rural and remote areas.

An increased focus on endometriosis in training through the RACGP and ACCRM could help prevent the diagnostic delay by facilitating early recognition, referral, and treatment.

6. Recognise endometriosis as a cause of disability.

Many of our members are unable to work due to their symptoms, particularly while waiting for access to intervention in the public system. Their only form of financial support is often JobSeeker, which is often not appropriate. They would like to see endometriosis recognised as a condition eligible for the Disability Support Pension if other criteria are met.

Endometriosis Western Australia is dedicated to advocating for Western Australians living with endometriosis. We appreciate your time and your efforts in developing Australian specific guidelines, but we believe that now is the time for significant revision to meet the needs and expectations of our diverse and well-educated community.

Our organisation is always available for consultation, and we are happy to facilitate direct consultation with our members. If there is anything else our organisation can do to assist with the development of a patient focused revision, we can be reached at info@endometriosiswa.org.au. We welcome the development of an ongoing relationship between our organisations and look forward to your future correspondence.

Yours sincerely,



Endometriosis
Western Australia Inc.

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