Australian Women's Lived Experiences of Asherman's Syndrome: Centre for Women's Health Research Submission to the Select Committee on Women's Health

About this submission

This submission was prepared by Ms Isabelle Barnes, Ms Zoe Crittenden, Ms Natalie Townsend, Ms Ella McConnochie, and Prof Deb Loxton and is made on behalf of the Centre for Women's Health Research, the University of Newcastle.

This submission focuses on findings from a qualitative study of 220 Australian women with Asherman's Syndrome. The study draws from data collected between June and August 2024, via an online survey conducted by Asherman's Australia. Key themes and quotes relating to women's lived experiences of Asherman's Syndrome are presented. While these quotes and findings are not representative of the population, they provide valuable insight into the lived experience of Asherman's Syndrome – an under-researched chronic women's health condition.

The findings presented in this submission are expected to be published in a peer-reviewed women's health journal in late 2026.

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Background

Asherman's Syndrome (AS) is an acquired gynaecological condition characterised by intrauterine adhesions.[1,2] Most cases arise following pregnancy-related procedures such as dilation and curettage (D&C).[1,3] Procedures involving sharp instruments (i.e. curettes) have a higher risk of causing scarring, compared to procedures which use vacuum or pharmacologically assisted evacuation.[4-10]

Despite claims that AS is a rare condition, clinical studies have estimated the prevalence to be as high as 45%, depending on the population, and incidence after a uterine curettage between 15% and 40%.[11] Given the lack of consensus regarding the prevalence and incidence of AS, describing the risk of AS as "rare" and "uncommon" prior to procedures known to cause the condition could be viewed as problematic.[12-14]

AS often goes undetected by standard clinical examinations and diagnostic scans (e.g. ultrasounds) and diagnosis typically requires invasive procedures, such as hysteroscopy.[3] Subsequent diagnostic delays and underdiagnosis can worsen symptoms and lead to additional health challenges for women with AS.[15,16]

Women living with AS report significant physical and reproductive consequences[17] including menstrual symptoms,[18,19] infertility,[20,21] recurrent pregnancy loss,[22,23] and chronic pain. However, there is a lack of research on the psychological impacts of AS. It is vital to comprehensively understand the impact AS has on women's lives more broadly to inform the development of effective women-centred and holistic care.

Australian women's lived experiences of Asherman's Syndrome

Thematic analysis of comments among Australian women with AS identified the following key themes:

- Inadequate risk communication
- Barriers to effective care
- Preventable harms
- Dismissal, medical gaslighting and erosion of trust
- Time loss and mental health strain
- Self-advocacy and information seeking
- Variability in care and uneven outcomes

Inadequate risk communication

Many women reported absent or inadequate pre-procedural counselling on the risks of AS prior to medical procedures, such as D&Cs. When mentioned by practitioners,

women reported the risk of AS was often downplayed, leading to women feeling misled after later being diagnosed with AS.

Barriers to effective care

Women reported multiple barriers that led to delays in, and prevented access to, diagnosis and treatment for AS. These included a lack of knowledge and awareness about AS among health practitioners and long travel distances and/or high costs associated with seeking specialist care.

Preventable harms

Women frequently discussed the prevention of AS through safer practices, timely interventions and adherence to evidence-based protocols. Specifically, women felt that alternative treatments to curettage procedures may have reduced their risk of developing AS.

Dismissal, medical gaslighting and erosion of trust

When seeking healthcare for symptoms associated with AS, women reported frequent instances of medical gaslighting. Such experiences left women feeling dismissed and ignored, without appropriate healthcare, and with greater mistrust towards health professionals more broadly.

Time loss and mental health strain

Many women felt that the persistent challenges associated with AS diagnosis and treatment lead to significant and ongoing mental health issues. Some women reported greater anxiety during fertility treatments, persistent fear of miscarriage, and regret over the time lost due to lack of treatment, which impacted their ability to build their families.

Self-advocacy and information seeking

The lack of awareness and information available regarding AS led women to online communities and resources to seek answers for their symptoms. Through these online networks (e.g. Facebook groups), many women reported that they have become “expert” patients and credit knowledge sharing between peers as a driving force in their own AS diagnosis and subsequent treatment.

Variability in care and uneven outcomes

Women consistently reported varying experiences in care for AS. Some described access to highly skilled specialists who performed hysteroscopic surgery and offered holistic, empathetic care. Others reported barriers that forced them to seek costly care interstate or privately.



Recommendations

Findings revealed that the harms of AS reported by women can extend beyond fertility loss, to include avoidable physical injury, psychological distress, and mistreatment by medical professionals. Women in this study consistently called for improved approaches to prevention, diagnosis, and treatment of AS.

These findings stress the urgent need for further population and clinical research into AS, including assessing practitioner knowledge and evaluating current guidelines for AS care. Such research is essential to improve the evidence base which informs prevention, diagnosis and treatment pathways for AS.

References

1. Yu DM, Wong Y-M, Cheong Y, et al. Asherman syndrome—one century later. *F & S* 2008; 89: 759-779. DOI: 10.1016/j.fertnstert.2008.02.096.
2. Royal Australian and New Zealand College of Obstetricians and Gynaecologists. Asherman Syndrome, https://ranzcog.edu.au/wp-content/uploads/2022/06/Asherman-Syndrome.pdf (2021, accessed 30 April 2024).
3. Smikle C, Yarrarapu SNS and Khetarpal S. Asherman Syndrome. *StatPearls*. Treasure Island (FL): StatPearls Publishing, 2025.
4. Kakinuma T, Kakinuma K, Sakamoto Y, et al. Safety and efficacy of manual vacuum suction compared with conventional dilatation and sharp curettage and electric vacuum aspiration in surgical treatment of miscarriage: a randomized controlled trial. BMC Pregnancy Childbirth 2020; 20: 695-695. DOI: 10.1186/s12884-020-03362-4.
5. Di Spiezio-Sardo A, Calagna G, Scognamiglio M, et al. Prevention of intrauterine post-surgical adhesions in hysteroscopy. A systematic review. Eur J Obstet Gynecol Reprod Biol X 2016; 203: 182-192. DOI: 10.1016/j.ejogrb.2016.05.050.
6. Sajan R, Pulikkathodi M, Vahab A, et al. Expectant Versus Surgical Management of Early Pregnancy Miscarriages- A Prospective Study. J Clin Diagn Res 2015; 9: Qc06-09. DOI: 10.7860/jcdr/2015/14803.6613.
7. Farooq F, Javed L, Mumtaz A, et al. Comparison of manual vacuum aspiration, and dilatation and curettage in the treatment of early pregnancy failure. J Ayub Med Coll Abbottabad 2011; 23: 28-31.
8. Acharya A, Prabhu A, Negi S, et al. Spontaneous miscarriage/abortion in the first trimester and expectant management – a meta-analysis approach. Prz Menopauzalny 2023; 22: 135-141. DOI: 10.5114/pm.2023.131307.
9. Manchanda R. Intra Uterine Adhesions: Diagnostic and Therapeutic Insight. 1st Edition 2021 ed. Singapore: Springer Singapore Pte. Limited, 2021.
10. Hira S, Shazia Mahmood A and Kashif S. Efficacy of Manual Vacuum Aspiration versus Dilatation and Curettage in First Trimester Miscarriages. Pakistan Armed Forces Medical Journal 2023; 73: 1326-1329. DOI: 10.51253/pafmj.v73i5.7201.
11. Dreisler E and Kjer JJ. Asherman's syndrome: current perspectives on diagnosis and management. Int J Womens Health 2019; 11: 191-198. 20190320. DOI: 10.2147/ijwh.S165474.
12. Queensland Health. Queensland Government Dilation & Curettage (D&C)/Suction Evacuation Consent, https://www.health.qld.gov.au/__data/assets/pdf_file/0030/1327863/SW9203.pdf (2024, accessed 22 June 2026).
13. The Private Clinic. The Private Clinic Consent for cervical dilatation & uterine curettage (D&C). https://www.privateclinic.com.au/wp-content/uploads/2015/10/Consent-DC-V1.3.pdf (n.d., accessed 22 June 2026).

14. Department of Health and Wellbeing. Government of South Australia Women's and Children's Health Network Surgical Management of Miscarriage, https://cdn.wchn.sa.gov.au/downloads/WCH/women/was/miscarriage-surgical-management-fact-sheet.pdf (2024, accessed 22 June 2026).
15. Khan K, Tariq N and Majeed S. Psychological Impact of Medical Gaslighting on Women: A Systematic Review. JPAP 2024; 5: 110-125. DOI: 10.52053/jpap.v5i1.249.
16. Moss CF, Chinna-Meyyappan A, Skovronsky G, et al. Experiences of Care and Gaslighting in Patients With Vulvovaginal Disorders. JAMA Netw Open 2025; 8: e259486-e259486. DOI: 10.1001/jamanetworkopen.2025.9486.
17. Humphries LA and Isaacson KB. Asherman Syndrome: An Updated Review on Diagnosis, Management, and Pregnancy Outcomes. Curr Obstet Gynecol Rep 2025; 14. DOI: 10.1007/s13669-025-00412-6.
18. Asherman JG. The menstrual cycle: amenorrhoea traumatica (atretica). Obstet Gynecol Surv 1948; 3: 850-851. DOI: 10.1097/00006254-194812000-00032.
19. Baradwan S, Baradwan A and Al-Jaroudi D. The association between menstrual cycle pattern and hysteroscopic march classification with endometrial thickness among infertile women with Asherman syndrome. Medicine (Baltimore) 2018a; 97: e11314-e11314. DOI: 10.1097/MD.0000000000011314.
20. Di Guardo F, Della Corte L, Vilos GA, et al. Evaluation and treatment of infertile women with Asherman syndrome: an updated review focusing on the role of hysteroscopy. Reprod Biomed Online 2020; 41: 55-61. DOI: 10.1016/j.rbmo.2020.03.021.
21. Di Spiezio-Sardo A, De Angelis MC, Dimitrios K, et al. Restoring Fertility of Patients with Severe Asherman's Syndrome in the Office Setting: A Step-by-Step Recipe for Success. J Minim Invasive Gynecol 2023; 30: 355-356. DOI: 10.1016/j.jmig.2023.02.002.
22. Baradwan S, Shafi D, Baradwan A, et al. The effect of endometrial thickness on pregnancy outcome in patients with Asherman's syndrome post-hysteroscopic adhesiolysis. Int J Womens Health 2018b; 10: 77-82. DOI: 10.2147/IJWH.S151283.
23. Qiao X, Liu D, Liu C, et al. Reproductive Outcomes After Hysteroscopic Adhesiolysis in Patients Experiencing Recurrent Pregnancy Loss and Intrauterine Adhesions. J Minim Invasive Gynecol 2025; 32: 57-63. DOI: 10.1016/j.jmig.2024.09.009.