

## **Endometriosis & Black Women: Fact Sheet**

# Myth Busters: Endometriosis & Black Women

#### Myth 1: "Black women don't get endometriosis."

**Reality**: Black women have historically been underdiagnosed due to medical biases. Research shows that Black women are just as likely—or even more likely—to have endometriosis, but they are diagnosed later and are more likely to be misdiagnosed with other conditions such as fibroids or pelvic inflammatory disease.

#### Myth 2: "Endometriosis is just bad period pain."

**Reality:** Endometriosis can cause pain throughout the body, not just during menstruation. Symptoms can include chronic pelvic pain, painful bowel movements, fatigue, and even pain in non-reproductive organs. Studies show that endometriosis-related pain is often dismissed in Black women, leading to delayed care.

# Myth 3: "Black women have a higher pain tolerance, so they don't need as much treatment."

**Reality**: This harmful stereotype has led to inadequate pain management for Black patients. Research confirms that Black women's pain is often underestimated and undertreated in medical settings. Pain from endometriosis is real and should be taken seriously.

# Myth 4: "Endometriosis is always linked to infertility, so if you can have kids, you don't have it."

**Reality**: While endometriosis can impact fertility, many people with endometriosis conceive naturally. The disease manifests differently in each person, and symptoms vary widely.

#### Myth 5: "Hysterectomy is the best cure for endometriosis."

**Reality**: Endometriosis is not cured by hysterectomy, as lesions can exist outside the uterus. The best treatment is excision surgery by a specialist, but access to this care is limited, especially for Black women due to healthcare disparities.

# Understanding Endometriosis & its impact on Black Women

Endometriosis is a chronic, systemic, inflammatory disease in which tissue similar—but not identical—to the uterine lining is found in other parts of the body. This can cause severe pain, organ dysfunction, adhesions, and a range of debilitating symptoms. It affects 1 in 10 individuals assigned female at birth (AFAB), but it has been found across all genders. There is no known cause or cure for endometriosis.

Black women are often underdiagnosed or misdiagnosed due to racial biases, lack of research, and healthcare disparities. Studies show that Black women are less likely to be diagnosed with endometriosis than white women, despite similar or even higher rates of symptoms. Delayed diagnoses can lead to worsened health outcomes, as untreated endometriosis can cause severe pain, infertility, and damage to multiple organs.

Black women experiencing symptoms of endometriosis are 50% less likely to be diagnosed with the condition than White women.

### **How to Get Support**

- Educate Yourself Learn about endometriosis through reputable sources, such as medical journals and advocacy groups.
- 2. **Communicate with Loved Ones** Help them understand what you're experiencing.
- 3. Seek Medical Help If a doctor dismisses your pain, get a second opinion. Request a referral to a gynecologist or an endometriosis specialist.
- 4. Get an Official Diagnosis The only definitive way to diagnose endometriosis is through laparoscopic surgery.
- 5. Find Culturally Safe Experts Look for healthcare providers who are trained in culturally competent care and understand Black women's health disparities.
- 6. **Use a Pain Log Book** Keep track of symptoms, pain levels, and triggers to help identify patterns and aid in diagnosis.
- 7. **Explore Different Treatments** Pelvic physiotherapy, acupuncture, and dietary changes can help manage symptoms.



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## Where to Find Culturally Safe Support

- The Endometriosis Coalition Provides advocacy and education on endometriosis, including healthcare equity. https://www.theendo.co
- The Black Women's Health Imperative (BWHI) Focuses on addressing health disparities for Black women. https://bwhi.org
- The Endometriosis Foundation of America (EndoFound) Offers resources, events, and expert information on endometriosis. <a href="https://www.endofound.org">https://www.endofound.org</a>
- Sister Girl Foundation. A national organization that supports Black women with various health conditions, including reproductive health. <a href="https://www.sister-girl.org">https://www.sister-girl.org</a>
- Melanin women endometriosis support (Facebook Group) A safe space for Black women to share their experiences
  and find recommendations for culturally competent doctors. <a href="https://www.facebook.com/people/Melanin-women-endometriosis-support/100063798523885/">https://www.facebook.com/people/Melanin-women-endometriosis-support/100063798523885/</a>
- Endometriosis Resources for the African, Caribbean, and Black Community- https://www.yourperiod.ca/
- The Endometriosis Network Canada (TENC) https://endometriosisnetwork.com
- Mino Care- https://www.minocare.ca

\*Please note this does not constitute medical advice or an opinion. Readers should not make decisions based on the information contained herein alone and should obtain professional medical advice on their specific circumstances. Reliance on the information contained herein is done sole at the readers own risk.\*

Behind the times: revisiting endometriosis and race. Bougie, Olga et al. American Journal of Obstetrics & Gynecology, Volume 221, Issue 1, 35.e1 - 35.e5; Bougie, O., Yap, M. I., Sikora, L., Flaxman, T., & Singh, S. (2019). Influence of race/ethnicity on prevalence and presentation of endometriosis: a systematic review and meta-analysis. BJOG: An International Journal of Obstetrics & Gynecology.; Fuldeore, M. J., & Soliman, A. M. (2017). Prevalence and symptomatic burden of diagnosed endometriosis in the United States. American Journal of Obstetrics & Gynecology.; Hoffman, K. M., Trawalter, S., Axt, J. R., & Oliver, M. N. (2016). Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites. Proceedings of the National Academy of Sciences.; Missmer, S. A., Hankinson, S. E., Spiegelman, D., Barbieri, R. L., & Marshall, L. M. (2004). Incidence of laparoscopically confirmed endometriosis by demographic, anthropometric, and lifestyle factors. American Journal of Epidemiology; Rogers, P. A., D'Hooghe, T. M., Fazleabas, A., Gargett, C. E., Giudice, L. C., Montgomery, G. W., ... & Taylor, R. N. (2009). Priorities for endometriosis research: recommendations from an international consensus workshop. Reproductive Sciences. The The Endometriosis Network Canada (TENC) - https://endometriosisnetwork.com.