

Have you heard of endometriosis?

A two minute guide for election candidates

What is endometriosis?

Endometriosis is a condition where cells similar to the ones lining the womb are found elsewhere in the body. This can lead to inflammation, pain, and the formation of scar tissue.

Endometriosis may have a significant, sometimes devastating, impact on all aspects of life: education, career, relationships, sexual relationships, fertility and quality of life. Despite this, it is a disease that many of the UK population have never heard of. Without awareness, the symptoms of endometriosis can be normalised and dismissed. However, without a diagnosis, treatment can't be accessed, and the disease may progress.

The average UK constituency has around 3600 voters living with endometriosis

Key statistics

- Endometriosis is the second most common gynaecological condition in the UK¹
- Polling in March 2024 revealed that only 53% of the UK public know that endometriosis is a gynaecological condition²
- In the UK, endometriosis affects 1.5 million women and those assigned female at birth³
- The prevalence of endometriosis in women experiencing infertility can be as high as 30 to 50%⁴
- Endometriosis costs the UK economy £8.2billion a year through treatment, loss of work and healthcare costs⁵
- The cause of endometriosis is unknown and there is currently no definite cure

It takes an average time of 8 years 10 months to receive a diagnosis of endometriosis in the UK

¹ University College London Hospitals. General information about Endometriosis. 2014.

² Censuswide. Nationally representative polling for Endometriosis UK. 2024.

³ Rogers PA, D'Hooghe TM, Fazleabas A, et al. Priorities for endometriosis research: recommendations from an international consensus workshop. Reprod Sci 2009;16(4):335-46.

⁴ Meuleman C, Vandenabeele B, Fieuws S, Spiessens C, Timmerman D, D'Hooghe T. High prevalence of endometriosis in infertile women with normal ovulation and normospermic partners. Fertil Steril 2009;92(1):68-74.

⁵ Simoens S, Dunselman G, Dirksen C, et al. The burden of endometriosis: costs and quality of life of women with endometriosis and treated in referral centres. Human Reproduction 2012;27(5):1292-9.



In England and Scotland, the average length of time to diagnosis is 8 years and 10 months. In Northern Ireland, this rises to 9 years and 5 months. In Wales, the current average diagnosis time is 9 years and 11 months⁶.

Endometriosis UK are calling for the four governments of the UK to commit to a target diagnosis time of 1 year or less by 2030. To learn more about how this should be achieved, <u>read our latest report</u>.

NHS gynaecology waiting times are unacceptable

In March 2024, there were 591,351 people waiting for gynaecology services in England alone. Since the start of the COVID-19 pandemic, gynaecology waiting lists have increased by over 60%: the biggest increase in any specialism⁷.

What can I do to help?

- 1. Speak up for the 1 in 10 women, and those assigned female at birth. We need more people to talk about the condition and to normalise conversations about menstrual health. <u>Contact Endometriosis UK today</u> for support in becoming an endometriosis champion in Parliament!
- 2. Show your support on social media using these handy <u>social media stickers</u>. We need to raise awareness and empower those with symptoms to go to their GP sooner.
- 3. Support the NHS to clear gynaecology waiting lists and help drive down diagnosis times. We need priority to be given to women's health, which has been overlooked for far too long.

About us

Endometriosis UK is the UK's leading charity for all those impacted by endometriosis.

We champion the rights and needs of those with endometriosis and are determined to ensure that everyone gets prompt diagnosis and the best treatment and support. The endometriosis community is at the heart of everything we do, and we strive to support and represent all experiences. We exist to provide vital support services, reliable information and a community for those affected by endometriosis.

For more information, please contact campaigns@endometriosis-uk.org.

⁶ Endometriosis UK. "Dismissed, ignored and belittled" The long road to endometriosis diagnosis in the UK. 2024.

⁷ Sloan R, Morris E, Walworth R, King R, Marsland A, Bray BD, Pearson-Stuttard J. EPH203 Estimating the Impact of COVID-19 Pandemic on Gynaecology Treatment in England. Value Health. 2022 Dec;25(12): S230.