



Endometriosis Policy Brief

Endometriosis: The Basics

Endometriosis is a condition where tissue similar to the lining of the uterus grows outside the uterus, causing inflammation and the formation of scar tissue. It affects around 1 in 10 people with a uterus¹ worldwide.¹ It is a chronic illness that can begin at menarche (first period) and last until menopause. Endometriosis can impact every aspect of a person's life interfering with their health and wellbeing, relationships, work and family planning.

Endometriosis is still not well known or understood. It affects more people than diabetes but it does not receive the same amount of attention, awareness and funding.² There are theories as to how endometriosis develops but without focused research and a strong evidence base it is difficult to create a treatment for endometriosis that tackles the root of the problem. Currently there is no cure or prevention, but various treatments to alleviate symptoms are available.

Symptoms

Endometriosis is characterised by pain in the pelvis, or lower part of the stomach. Those suffering with endometriosis often find that this pain is exacerbated during menstruation, sex, urination or defecation. Yet many with this condition experience no symptoms, making it difficult to diagnose. Endometriosis has been linked to infertility and some people only discover they have the condition when trying to conceive. Other symptoms may include bloating, nausea, heavy bleeding during menstruation, anxiety and depression.

Long Delays

The time to receive a diagnosis takes 7.4 years on average from the onset of symptoms to the receipt of a diagnosis of endometriosis.³

One of the main causes of the delay in diagnosing endometriosis is that symptoms can vary from person to person and many of the symptoms of endometriosis are similar to other conditions.⁴ Some people with advanced stage endometriosis can have no symptoms, while those at an early stage can experience excruciating pain.

There is a misunderstanding among the general public and healthcare professionals that pain is normal for women particularly around the time of menstruation, and this adds to the diagnostic

¹ This article aims to use gender-neutral language where possible. When the word woman is used in the text it includes transgender and gender non-conforming people.

delay for endometriosis. (4) Furthermore, there is a lack of knowledge and awareness of the condition among the public and healthcare providers.⁵⁻⁸

A negative attitude towards menstruation, whereby it was not spoken about in adolescence or carried shame, can also add to the stigma of endometriosis.⁹ Thus, those who feel that endometriosis is a taboo subject are less likely to speak openly about their symptoms and seek professional help.

Studies suggest that adolescents experience even longer endometriosis diagnostic delays.⁸ This is due to a number of reasons such as different presentations of the condition in adolescents compared to adults; delay in attending a healthcare facility; reluctance of the healthcare provider to perform the surgery needed to diagnose endometriosis in adolescents; and lack of adolescent knowledge around endometriosis, among other reasons. Furthermore, some women report being mistakenly told that they are too young to have endometriosis.¹⁰

Treatment

Treatments are available to help control the symptoms of endometriosis but there is currently no cure for the condition. These can include hormonal treatments, surgery and others recommended by healthcare providers.

Endometriosis and Fertility

16 – 40% of people with endometriosis experience infertility.¹¹ This can be due to physical disturbances such as a blockage in the fallopian tubes, where the egg is normally released, not allowing it to fuse with sperm. Endometriosis can also affect the quality of eggs released, making them less likely to be fertilised and form an embryo that can develop and implant effectively.

In some cases a doctor may prescribe a fertility treatment to increase a person's chances of getting pregnant. Some treatments that may be recommended include stimulating the ovaries to make more eggs and in-vitro fertilisation.

Endometriosis, Work and Education

Endometriosis can be an extremely debilitating condition. It can impact all areas of a person's life including their personal life, education and work.

Studies have shown that endometriosis affects quality of life as well as productivity at work.¹² This can result in reduced income for those with endometriosis compared to those without endometriosis. Endometriosis sufferers miss more days of work compared to those who don't have the disease.¹³ Women have cited endometriosis as a factor inhibiting their career and salary growth.¹¹ A lack of support and policies for female sex-specific conditions, contribute to the gender pay gap. The negative effect of endometriosis is replicated in education.¹¹ Endometriosis is linked to school absenteeism; it impairs a person's ability to do their schoolwork; and it is listed as a reason for not pursuing further education.

The Social and Psychological Impact of Endometriosis

A survey from the US showed that 50% of women with endometriosis had stayed in bed all day at some point in the past 12 months because of the pain associated with the condition.¹¹ Endometriosis can impact the social lives of those affected, causing them to withdraw from social interactions due to the symptoms associated with the condition. Endometriosis has been linked with low self-esteem, body image issues and mental health conditions such as anxiety and depression.

Endometriosis can also affect personal relationships. Painful sex is one of the symptoms of endometriosis and those in this category report less satisfaction with their sex life, and less sexual interest and pleasure.^{11, 14} Many people with endometriosis are advised to consider family planning early due to the risk of future infertility. This can cause anxiety and disrupt personal, educational and career plans.

Endometriosis Policies in Europe

The European Parliament has estimated that the annual cost of endometriosis-related leave is €30 billion.¹⁵ This could be drastically reduced with timely diagnosis and treatment. Endometriosis policies in Europe are in a nascent stage with some promising developments, however, it is too early to ascertain whether these have had an effect on diagnostic times, patients' quality of life and other important indicators and outcomes.

In 2022 France launched a national strategy for endometriosis.¹⁶ This will increase awareness, address diagnostic delays and advance the treatment of this condition by allocating designated treatment centres in various regions across the country. The plan aims to foster research on the disease and increase education of the condition among healthcare professionals. While broadly welcomed, the strategy lacks a concrete timeline with specified targets and outcomes, and dedicated funding.

Ireland launched a Women's Health Action Plan 2022 – 2023, which includes the introduction of two endometriosis hubs for specialist care.¹⁷ Similarly, Scotland has a national Women's Health Plan¹⁸ which aims to reduce endometriosis diagnosis waiting times from 8 years to under 12 months. There are a host of important goals in this strategy that could be harnessed in other contexts. Existing programmes for women of reproductive age such as the HPV vaccination programme will be used to educate service users on menstrual health, taking advantage of a life-course approach. Each primary care team will have a designated healthcare professional specialising in menstrual health, who women can be referred to for expert advice on conditions such as endometriosis. Scotland also plans to commission research on endometriosis to better understand the pathology and pathways involved so that targeted treatments can be researched and developed.

Spain is the first country in Europe to provide paid menstrual leave.¹⁹ Those who menstruate are entitled to three days per month, with the option to extend it to five days, for painful periods. This leave will be paid for by the state's social security system rather than employers. This legislation is particularly important for endometriosis sufferers as dysmenorrhea is a common symptom.

In 2020, Scotland was the first country in the world to make menstrual products free in public buildings, in an effort to tackle period poverty and promote gender equality.²⁰ In 2023, France made reusable menstrual items such as reusable pads and menstrual cups free for the under 25s.²¹ Between 2023 and 2025 Catalonia will begin rolling out a similar initiative offering students free reusable menstrual products.²² While this is an important first step, it is salient to note that period poverty does not only affect younger people and free menstrual products should be offered to all who menstruate.

Recommendations

1. Endometriosis is a public health issue and an unmet medical need. The European Institute of Women's Health advocates for inclusive public health campaigns on the topic of endometriosis to raise awareness of this condition among the public and healthcare professionals, and to reduce the stigma and misinformation surrounding this condition.

2. Ensure that everyone in Europe has access to high quality treatment and support for endometriosis. Specialist endometriosis centres are recommended to ensure quality and excellence in care. By centralising care, resources can be used more effectively and women's treatment regimens can be harmonised. Support should always be provided to patients in a timely and holistic manner. Centres of excellence can also act as specialist research hubs for endometriosis.
3. Training and education of healthcare professionals are needed to position patients as experts in their symptoms and disease. Patients should be routinely provided with a thorough description of the options available in layman's terms and shared decision-making must become the norm. The involvement of patients in healthcare professional education, across the diagnostic pathway would support the early diagnosis of endometriosis.
4. Menstrual leave is advocated for, in particular, due to the debilitating nature of dysmenorrhea associated with endometriosis.
5. Menstrual education must be mandatory in schools so that women are aware of what is considered normal and when to seek professional care. This must be age-appropriate and taught to all children regardless of gender in primary and secondary schools.
6. Financial barriers must be removed for endometriosis care. Thus, those with the condition must not pay out-of-pocket for care. Support and education on contraception and family planning must be freely available, appropriate and ongoing across Europe.
7. More research is needed on endometriosis to better understand the disease pathway and to develop targeted treatments and prevention strategies. Endometriosis must become a priority for research at EU and national level. Horizon Europe, Innovative Health Initiative and the EU4 Health programme must include endometriosis in future funding programmes. Furthermore, there must be diversity in clinical trials to ensure the safety and efficacy of endometriosis treatments.
8. Fertility treatments must be free, accessible and high quality to all those experiencing infertility. This is particularly relevant to those with endometriosis who have a higher prevalence of fertility problems compared to those without endometriosis.
9. Mental health prevention, treatment and survivorship policies must be prioritised within Europe. This is important for endometriosis patients, as the condition is associated with anxiety, depression, body issues and low self-esteem.

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