

ENDOMETRIOSIS UK SEEKS SCOTTISH PARLIAMENT ENDOMETRIOSIS CHAMPIONS



We are asking candidates in the 2021 Scottish Parliament elections to commit to becoming an **Endometriosis Champion** should they get elected. If you are successful in becoming an MSP on 6 May, you can then help us improve endometriosis care in Scotland through:

1. **Faster diagnosis** - Reduce diagnosis time for endometriosis to an average of four years by 2025 and under one year by 2030
2. **Ensure a baseline of care** - Ensuring everyone with endometriosis in Scotland gets access to care and support in line with NICE guidance¹
3. **Menstrual wellbeing education** – Mandatory age-appropriate menstrual well-being education in all Scottish primary and secondary schools

If you would like to signal your intention to become an Endometriosis champion or if you have any questions, please email: communications@endometriosis-uk.org.

OUR ASKS FOR ENDOMETRIOSIS IN SCOTLAND

1. FASTER DIAGNOSIS

Why? Waiting an average of 8.5 years to be diagnosed means people with endometriosis in Scotland suffer both physically and mentally while not getting the right care, nor a name for their symptoms. The delay may result in the disease progressing, along with the distress of repeated GP and hospital visits that fail to identify a cause for symptoms. It is also a poor use of NHS resources.

Current situation: A 2020 survey² found that prior to diagnosis, people with endometriosis in Scotland:

- visited their GP more than ten times with symptoms (61% of respondents)
- had more than 5 hospital appointments due to symptoms (43%) had more than 10 (22%)
- went to A&E with symptoms (55%), more than three times (24%)

Action needed: A commitment from the Scottish government to reducing diagnosis time down to under four years on average by 2025 and under one year by 2030. This requires improving public and healthcare practitioner awareness of the signs and symptoms of endometriosis and better diagnostic referral pathways.

2. ENSURING A BASELINE IN ENDOMETRIOSIS CARE

Why? Failure to get the right care may result not only in declining physical and mental health, but also days lost in the workplace and education damaging employment and educational prospects, and sometimes leading to financial stress.

Current situation: A 2020 survey² found that people in Scotland had long delays in getting referred for hospital appointments. The same survey found that when people with endometriosis were told they needed surgery:

¹ NICE guidance NG73 on Endometriosis: diagnosis and management, 6 September 2017 <https://www.nice.org.uk/guidance/NG73> and Quality Standards QS172 on Endometriosis, 6 August 2018 <https://www.nice.org.uk/guidance/QS172>

² *Endometriosis in the UK – Time for Change*, Inquiry Report of APPG on Endometriosis, October 2020 <https://www.endometriosis-uk.org/sites/endometriosis-uk.org/files/Endometriosis%20APPG%20Report%20Oct%202020.pdf>

- 26% waited more than 6 months (UK average 30%)
- 6% waited more than a year (UK average 7%)

These figures are pre-Covid, and we know from speaking to people with endometriosis in Scotland that the pandemic has made the situation worse by leading to appointments and treatment being cancelled or postponed.

There are three endometriosis specialist centres in Scotland (in Edinburgh, Glasgow and Aberdeen). These centres are currently funded and commissioned on a local level, which results in difficulties for people outside the relevant Health Board areas to get referrals. Endometriosis care is currently being examined in Scotland as part of a review on women's health. The creation of a national endometriosis service is being considered, but no decisions have yet been made.

Action needed: The next Scottish government should commit to creating a national service for endometriosis care in Scotland which:

- Incorporates the three specialist centres in a hub and spoke model
- Respects the relevant NICE guidance ([NICE guidelines \(NG73\)](#)) and [quality standards \(QS172\)](#)

3. MENSTRUAL WELLBEING EDUCATION

Why? When children and young people do not know what is normal and what is not in relation to periods and menstrual health, those with endometriosis can suffer in silence as well as miss out on education. The 2020 survey³ revealed that 34% of pupils with endometriosis have missed school and 12% have missed exams. Age-appropriate menstrual wellbeing education can help children to know when something is wrong and how to speak to someone about it, so they can be diagnosed and receive care, which may help avoid missing out on education.

Current situation: There are schools in Scotland that teach menstrual wellbeing as part of the Curriculum for Excellence initiative, but this is not compulsory and therefore does not happen in all schools.

Change needed: The introduction of mandatory age appropriate menstrual wellbeing education in primary and secondary schools across Scotland.

ENDOMETRIOSIS IN SCOTLAND – FACTS AND FIGURES

- Around 1 in 10 women and people assigned female at birth in Scotland have endometriosis.
- It takes on average 8.5 years to be diagnosed with endometriosis in Scotland, longer than the 8 year UK average.
- Prior to diagnosis, a person with endometriosis symptoms in Scotland makes repeated visits to the GP (61% make 10 or more), a number of hospital visits (43% make more than 5) and even present at A&E (55% visit A&E).
- There are three BSGE (British Society of Gynaecological Endoscopy) endometriosis specialist centres in Scotland (in Edinburgh, Glasgow and Aberdeen). These centres are currently funded and commissioned on a local basis.

³ *Endometriosis in the UK – Time for Change*, Inquiry Report of APPG on Endometriosis, October 2020 <https://www.endometriosis-uk.org/sites/endometriosis-uk.org/files/files/Endometriosis%20APPG%20Report%20Oct%202020.pdf>

- There are no care pathways in Scotland for people with endometriosis outside the pelvic cavity (estimated to be between 5% and 10% of cases).
- There are [NICE guidelines \(NG73\)](#) and [quality standards \(QS172\)](#) on endometriosis, but they are not fully implanted in Scotland.
- Endometriosis UK is currently undertaking an audit of endometriosis care in Scotland funded by the Scottish government.

ABOUT ENDOMETRIOSIS

Endometriosis is a condition where cells similar to the ones lining the womb are found elsewhere in the body, usually within the pelvic cavity. Each month these cells react to the menstrual cycle in the same way to those in the womb, building up and then breaking down and bleeding. Unlike the cells in the womb that leave the body as a period, this blood has no way to escape. This leads to inflammation, pain, and the formation of scar tissue (adhesions).

The condition affects 1.5million in the UK; approximately 1 in 10 women and those assigned female at birth from puberty to menopause, although the impact may be felt for life. There is no cure for endometriosis and the cause is not known.

Endometriosis symptoms can vary in intensity from one person to another. Whilst for some they may experience only mild symptoms or none at all, for others it can be debilitating. Whilst not every person will suffer from every symptom, common symptoms include:

- Pelvic pain
- Painful or irregular periods
- Pain during or after sex
- Painful bowel movements
- Pain when urinating
- Fatigue
- Difficulty getting pregnant

ABOUT US

Endometriosis UK is the UK's largest charity supporting people affected by endometriosis in the UK. We support those with the condition through the provision of information through [our website](#) and information leaflets, and direct support through a helpline, support groups, and an online forum. We also raise awareness to improve the lives of all those affected by endometriosis, and are involved in research.

If you have any questions or would like to find out more, please email: communications@endometriosis-uk.org.