

ENDOMETRIOSIS UK SEEKS WELSH SENEDD ENDOMETRIOSIS CHAMPIONS

We are asking candidates in the 2021 Welsh Senedd elections to commit to becoming an **Endometriosis Champion** should they get elected. If you are successful in becoming an MS on 6 May, you can then help us improve endometriosis care in Wales 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 Wales gets access to care and support in line with NICE guidance¹ and the recommendations of the 2018 Welsh government review on endometriosis care²
3. **Menstrual wellbeing education** – Ensure the implementation of mandatory age-appropriate menstrual well-being education in all Welsh 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 WALES

1. FASTER DIAGNOSIS

Why? Waiting an average of 9 years to be diagnosed means people with endometriosis in Wales 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 survey³ found that pre-diagnosis, people with symptoms of endometriosis in Wales:

- 56% visited their GP more than ten times
- 37% had 5 or more hospital appointments, 23% had more than 10
- 59% went to A&E, and 26% went to A& E more than three times (26%)

Action needed: A commitment from the Welsh government to reduce diagnosis time down to on average under four years by 2025 and under one year by 2030. This requires improving public and healthcare practitioner awareness of the signs and symptoms of endometriosis as well as implementing referral pathways for diagnosis.

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.

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 care in Wales: Provision, care pathway, workforce planning and quality and outcome measures*, Report of the Welsh Government Endometriosis Task and Finish Group, 16 April 2018 <https://gov.wales/sites/default/files/publications/2019-03/endometriosis-care-in-wales-provision-care-pathway-workforce-planning-and-quality-and-outcome-measures.pdf>

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>

Current situation: The 2018 Welsh government review on endometriosis care⁴ concluded that “service provision across primary, secondary, and tertiary care is not meeting need, resulting in lack of access to appropriate care for women across Wales”. A 2020 survey⁵ found that people in Wales experienced delays in getting referred for hospital appointments.

The same survey found that when people with endometriosis were told they needed surgery:

- 48% 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 Wales that the pandemic has made the situation worse through appointments and treatment being cancelled or postponed.

There is currently only one BSGE accredited endometriosis centre in Wales at University Hospital of Wales in Cardiff, and a second provisional centre at the Singleton Hospital in Swansea. People who need specialist surgery that can only be provided at the Cardiff centre are being turned away and told there is no funding available as they are ‘out of area’. People in North Wales who need specialist care tend to be referred to the BSGE centres at Arrows Park Hospital in Birkenhead, near Liverpool or the Countess of Chester hospital in Chester, and while cross-border referral arrangements exist, they are not always used.

A 2018 Welsh government review *Endometriosis care in Wales: Provision, care pathway, workforce planning and quality and outcome measures*⁴ recommended an enhanced service and improvements are beginning to happen. For example, NHS Wales recently announced the appointment of an endometriosis specialist nurse for each Welsh Health Board, which we welcome.

Action needed: The next Welsh government should commit to improving and streamlining endometriosis care in Wales including implementing:

- the recommendations of the 2018 Welsh government review on endometriosis care⁴
- 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 as well as a range of other menstrual conditions can suffer and miss out on their education. The 2020 survey⁵ revealed that 34% of those with endometriosis have missed school and 12% have missed exams. Age-appropriate menstrual wellbeing education can help children to identify if something is wrong and how to speak to someone about, so they can be diagnosed and receive care, which in turn may help avoid missing out on education.

Current situation: Whilst the (2016-21) Education Minister agreed in principle on to introduce menstrual wellbeing education in all Welsh schools, this has not yet been implemented.

Action needed: Ensure that menstrual wellbeing education is implemented in Wales.

⁴ *Endometriosis care in Wales: Provision, care pathway, workforce planning and quality and outcome measures*, Report of the Welsh Government Endometriosis Task and Finish Group, 16 April 2018 <https://gov.wales/sites/default/files/publications/2019-03/endometriosis-care-in-wales-provision-care-pathway-workforce-planning-and-quality-and-outcome-measures.pdf>

⁵ *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>

ENDOMETRIOSIS IN WALES – FACTS AND FIGURES

- 1 in 10 women and people assigned female at birth have endometriosis in Wales.
- It takes on average 9 years to be diagnosed with endometriosis in Wales, longer than the UK average of 8 years.
- Prior to diagnosis, many people experiencing symptoms of endometriosis in Wales make repeated visits to the GP (56% make ten or more visits), a number of hospital visits (39% make five or more), and end up in A&E (59%)⁶.
- There is one BSGE (British Society of Gynaecological Endoscopy) accredited endometriosis specialist centre in Wales at the University Hospital of Wales in Cardiff, and a second provisional centre at the Singleton Hospital in Swansea.
- There are no care pathways in Wales for people with endometriosis outside the pelvic cavity (estimated to be between 5-10% of those with endometriosis).
- There are [NICE Guideline \(NG73\)](#) and [Quality Standards \(QS172\)](#) on endometriosis, but they are not fully implemented in Wales.
- The Welsh government undertook [a review of endometriosis services in 2018](#), which made some very good recommendations, but they have not yet been fully implemented.

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.

⁶ *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>