

CALL FOR NORTHERN IRELAND ASSEMBLY ENDOMETRIOSIS CHAMPIONS

We are asking candidates in the 2022 Northern Ireland Assembly elections to commit to:

- (a) Becoming an **Endometriosis Champion** in the next Assembly if elected an MLA on 5th of May
- (b) Encouraging their party (if involved in negotiations) to push for the inclusion of commitments on endometriosis in the next Northern Ireland Programme for Government

Improving endometriosis care in Northern Ireland requires:

1. **Baseline of endometriosis care for all** – Ensuring everyone with endometriosis in Northern Ireland gets access to care and support in line with NICE guidance¹ including access to specialist care.
2. **Faster diagnosis** – Reduce average time it takes to get a diagnosis of endometriosis from 8.5 years to four years by 2025 and under one year by 2030.
3. **Tackling pandemic backlog** – ensuring appropriate action and resources to tackle gynaecology backlog in particular for those with severe endometriosis who had surgery cancelled or postponed.
4. **Menstrual wellbeing education** – Ensuring age-appropriate comprehensive menstrual wellbeing education in all Northern Irish schools to improve awareness and understanding of menstrual health including endometriosis.

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

OUR ASKS FOR ENDOMETRIOSIS IN NORTHERN IRELAND

1. BASELINE OF ENDOMETRIOSIS CARE FOR ALL

Why? Failure to get the right care can result in declining physical and mental health as well as days lost in the workplace and education damaging career and educational prospects, and generating financial stress.

Current situation: A 2020 survey² found that people in Northern Ireland had long waits for gynaecology appointments and surgery:

- 61% waited more than 6 months for a gynaecology appointment (UK average 24%)
- 57% waited more than 6 months for surgery (UK average 30%)
- 25% waited more than a year for surgery (UK average 7%)

The data above was pre-Covid and we have heard from the endometriosis community in Northern Ireland that the waiting times situation has now got worse due to the pandemic.

There is currently no fully accredited BSGE endometriosis specialist centre³ in Northern Ireland as the centre at Altnagelvin Hospital, part of the Western Health and Social Care Trust is no longer operating. There is a provisional BSGE centre at the Mater Hospital, part of the Belfast Health and Social Care Trust⁴. In March 2022, the Northern Ireland Health Minister said that the Belfast centre was developing a business case to become a fully accredited BSGE centre, and it was hoped that the BSGE centre at the Altnagelvin hospital could be reinstated in 2022 or 2023. Both trusts would need to secure funding to enable them to become BSGE accredited endometriosis specialist centres.

NICE guidance states that those with suspected or confirmed deep endometriosis involving the bowel, bladder or ureter (around 1% of cases⁵) must be seen in an endometriosis specialist centre. Currently those patients have nowhere to go in Northern Ireland, a situation which urgently needs addressing.

Action needed:

- Implement [NICE guideline NG 73](#) and [NICE quality standard QS 172](#) including ensuring endometriosis specialist centre provision in Northern Ireland by supporting the Belfast and Western Trusts to become BSGE centres.
- This could be aided by an audit to identify gaps and challenges to implementation.
- Measure and meet the demand for endometriosis care in Northern Ireland to ensure timely access and sufficient provision.
- Address gaps in existing NICE guidance including access to pain management services, care pathways for endometriosis outside the pelvic cavity starting with thoracic and integration of mental health support.

2. FASTER DIAGNOSIS

Why? Waiting an average of 8.5 years to get a diagnosis of endometriosis in Northern Ireland means many with the condition 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 HSCNI resources.

Current situation: A 2020 survey¹ found that prior to diagnosis, those with endometriosis in Northern Ireland:

- 60% visited their GP more than ten times with symptoms
- 42% had more than 5 hospital appointments due to symptoms, 23% had more than 10
- 60% went to A&E with symptoms, 30% more than three times

Action needed:

- A commitment to reduce diagnosis time down to under four years on average by 2025 and under one year by 2030 which will involve: clear pathways for diagnosis, investment in diagnostic capacity in gynaecology departments, and improving healthcare practitioner and public awareness and understanding of endometriosis.

3. TACKLING PANDEMIC BACKLOG IN GYNAECOLOGY

Why? To stop further delays to care and deal with those who have been waiting a long time for a gynaecology appointment or for a date for surgery.

Current situation: Waiting times for gynaecology appointments and surgery have got longer due to the pandemic. This is a particular problem for those waiting for specialist surgery due to the lack of BSGE endometriosis specialist centre provision in Northern Ireland.

Action needed:

- Allocate sufficient resources to tackling the gynaecology backlog.
- Prioritise those waiting for endometriosis care according to clinical need, for example using the RCOG Covid-19 prioritisation framework⁶; particularly important for those with severe endometriosis who had surgery postponed or cancelled.

4. MENSTRUAL WELLBEING EDUCATION

Why? It is essential that children and teenagers know what is normal and what is not in relation to periods and menstrual health, so those with endometriosis can seek help rather than suffering in silence and missing out on

education. The 2020 survey² revealed that 34% of pupils with endometriosis have missed school and 12% have missed exams.

Current situation: Northern Irish schools have the option to teach their pupils about period dignity and menstrual wellbeing and there is training for teachers and teaching materials available. It is not mandatory and does not take place in all schools. In December 2021 the Education Minister Michelle McIlveen MLA reported that 394 teachers had undergone the period dignity/menstrual wellbeing training.

Action needed:

- Ensure all school children in Northern Ireland receive age appropriate menstrual wellbeing education to equip them to recognise potential problems such as endometriosis and seek help.

ABOUT ENDOMETRIOSIS

Endometriosis is a condition where cells similar to those lining the womb are found elsewhere in the body, usually within the pelvic cavity. Each month these cells react to the menstrual cycle building up and then breaking down and bleeding, but unlike 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 in 10 women and those assigned female at birth from puberty to menopause, although the impact may be felt for life – that's 1.5 million in the UK. There is no cure for endometriosis although treatments to manage symptoms exist, and the cause is not yet known.

Some with endometriosis may experience only mild symptoms or none at all, while for others it can be chronic and debilitating. Common symptoms include chronic pelvic pain, painful periods, pain upon urination, painful bowel movements, fatigue and difficulties getting pregnant.

ABOUT ENDOMETRIOSIS UK

Endometriosis UK is the UK's leading charity supporting those 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: policy@endometriosis-uk.org.

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

³ British Society of Gynaecological Endoscopy (BSGE) [accredited endometriosis specialist centres](#)

⁴ [Belfast provisional BSGE centre](#)

⁵ Wild et al (2019) [Medical management of deeply infiltrating endometriosis - 7 year experience in a tertiary endometriosis centre in London](#), Gynaecology Surgery, volume 16, Article number 12, 3 December 2019

⁶ [Restoration and Recovery: Priorities for obstetrics and gynaecology – a prioritisation framework in response to Covid-19](#), Royal College of Obstetricians and Gynaecologists, last updated 21 April 2021