

Wes Streeting MP  
Secretary of State for Health and Social Care  
Department of Health and Social Care

39 Victoria Street  
London  
SW14 QEU

4 March 2026

Dear Secretary of State,

### **Endometriosis and Fertility: A Call for Defined National Action**

I am writing as the Founder and Chief Executive of The Endometriosis Foundation. Since 2018, our work has focused on improving understanding of endometriosis, reducing diagnostic delay, strengthening access to specialist care and ensuring that patient voice informs policy and practice.

This issue is deeply personal. I was diagnosed with severe endometriosis and infertility at the age of 25, despite being under gynaecological care from the age of 14. My experience reflects a wider reality. Delayed diagnosis and fragmented care pathways continue to shape reproductive futures, increase clinical complexity and affect long-term wellbeing for many of those living with this condition.

Today, we write alongside clinicians, researchers, parliamentarians and patient representatives gathered in Parliament for Endometriosis & Fertility Action Day. While our work spans the full endometriosis pathway, today's focus is fertility - an area that remains insufficiently reflected within national care pathways.

Endometriosis affects at least 1 in 10 women and those assigned female at birth in the UK. The condition is associated with infertility in an estimated 30–50% of those affected and is also linked to increased risks during pregnancy, including ectopic pregnancy, placental complications such as placental abruption, preterm birth and miscarriage in some groups.

Despite this, the condition continues to be characterised by:

- An average diagnostic delay of **7-9 years**
- Inconsistent access to specialist services
- Regional variation in fertility treatment provision
- Delayed or absent fertility counselling at diagnosis

Our national survey of over **1,100 individuals** found:

- **70%** report concern about their future fertility
- Only **48%** were aware of fertility implications at diagnosis
- Just **17%** were informed by a clinician about the link between endometriosis and infertility

- Over **90%** reported experiencing anxiety or low mood linked to their condition

Fertility is not a peripheral issue within endometriosis care. It is central to informed choice.

Too often, fertility discussions take place only after disease progression, repeated surgery or years of unmanaged symptoms. Some patients self-fund fertility preservation or IVF at significant personal cost and under considerable time pressure, while others continue trying to conceive without clear information about how their options may change over time.

## **A System Under Strain**

The current diagnostic delay of **7-9 years** means that many individuals reach specialist care late in the course of their disease. Where referral to a specialist centre is required, patients may wait an additional **one to three years** for advanced assessment or surgical care.

For a woman experiencing symptom onset aged 26, this could mean diagnosis at 34, as her natural fertility window begins to narrow.

Delay does not only affect fertility. It may lead to:

- More advanced disease at presentation
- Increased need for complex or multi-organ surgery
- Repeated procedures and recovery periods
- Psychological distress associated with uncertainty or dismissal
- Disruption to education, employment and financial stability

Earlier diagnosis and clearer referral pathways help protect reproductive choice, reduce clinical complexity and support long-term wellbeing.

## **Our Calls to Action**

We respectfully ask that the Government consider the following measures:

1. **Embedding structured fertility counselling** within national endometriosis pathways at the point of diagnosis.
2. **Ensuring equitable access to fertility preservation** for individuals at risk of fertility loss, regardless of postcode.
3. **Strengthening integration between endometriosis specialist centres and fertility services** to streamline referral pathways.
4. **Commissioning a national endometriosis registry** to improve data collection on diagnosis, treatment, fertility and pregnancy outcomes.
5. **Reducing diagnostic delay** through targeted clinician education and clearly defined referral standards across primary, secondary and tertiary care.
6. **Developing guidance for preconception counselling and antenatal monitoring** for those with moderate to severe disease.
7. **Strengthening the specialist workforce in advanced endometriosis surgery**, including expanded training opportunities and support for regional specialist centres.

These recommendations align with the Women's Health Strategy and the NHS commitment to prevention, equity and timely care.

## **From Patient Voice to Policy**

Endometriosis is a chronic, inflammatory and often multi-system condition that may involve the bowel, bladder, diaphragm, lungs and other organs. Its impact extends far beyond reproductive health alone.

Across clinical evidence and lived experience, the message is clear: fertility must no longer be treated as an afterthought within endometriosis care.

Shortening delay protects reproductive choice.

Clearer conversations protect autonomy.

Integrated pathways protect outcomes.

We stand ready to work collaboratively with the Department of Health and Social Care to support practical, measurable progress and would welcome the opportunity to discuss how these priorities can be embedded within future policy development.

Yours sincerely,

Carla Cressy OBE

On behalf of The Endometriosis Foundation

And the undersigned clinicians, organisations and parliamentarians