



All Party Parliamentary Group

Endometriosis

Endometriosis (Not) In The Workplace

Report of the All-Party Parliamentary Group on Endometriosis

October 2026



This is not an official publication of the House of Commons or the House of Lords. It has not been approved by either House or its committees. All-Party Parliamentary Groups are informal groups of Members of both Houses with a common interest in particular issues. The views expressed in this report are those of the group.

Endometriosis UK provides the secretariat to the All-Party Parliamentary Group on Endometriosis and provided administrative support for this inquiry. This report was drafted by Pulse Consultancy, commissioned and funded by Endometriosis UK in its role as secretariat to the APPG, drawing on the evidence received by the inquiry. The findings and recommendations are those of the APPG.

Contents

Forewords	4
What is endometriosis?	7
Executive Summary	9
About the Inquiry	13
The impact of endometriosis at work	15
Support, adjustments and fair treatment	19
Recommendations	25
Acknowledgements	28

Forewords



Kirsteen Sullivan MP

The impact of endometriosis on work is as unique and individual as the condition itself. We understood the scale of the crisis in endometriosis diagnosis waiting times, pain management and treatment. Unfortunately, too many know the story personally.

We began this inquiry to better understand what having endometriosis actually means for women at work. The response was remarkable. Over 6,000 people responded to our employee survey, sharing unique experiences from a range of workplaces. Each story we received had its own challenges and difficulties where women just wanted to work and contribute.

For many, this meant sharing experiences which were extremely personal, and often for the first time. We heard from women who had worked through severe pain because they are afraid of automated absence monitoring; encountered dismissive and hostile management; and so many whose careers had stalled or ended altogether. I thank each person who took the time to contribute.

Those experiences are difficult to read and hear. To me, this report should be a voice to those women who have felt dismissed. Though their situations and symptoms are distinct and individual, their experiences at work are not in isolation. I hope they found validation in the inquiry, as we listened and learned.

This report also contains examples of what happens when people get the right support. We want to learn from and champion the managers who listened, employers who were flexible, and the simple changes which make remaining in work possible. I believe it shows that the outcomes and challenges faced by women with endometriosis are not inevitable.

There is no single workplace experience of endometriosis. The condition affects all people differently. Someone working in an office will face different practical challenges from somebody working on a railway, in health or care services, security and policing, or in a factory.

The varied experiences shared with us all had one thing in common: a call for dignity and respect at work. A call for listening, understanding and a human response to their needs. No one should feel that being open about their health will cost them a promotion, their income or their job.

Finally, my sincere thanks go to everyone who has contributed to this inquiry and to the considerable work involved in bringing this evidence together. Most importantly, I thank those living with endometriosis who trusted us with their experiences. We have a responsibility now to make sure that trust leads to change.

Kirsteen Sullivan MP

Chair, All-Party Parliamentary Group on Endometriosis

ENDOMETRIOSIS (NOT) IN THE WORKPLACE

Report of the All-Party Parliamentary Group on Endometriosis



Emma Cox, CEO of
Endometriosis UK

Women and those assigned female at birth with endometriosis want what anyone wants from working life: the opportunity to do their job well, build a career and fulfil their potential. Too often, what stands in their way is not their ability, but a workplace that fails to provide the right support when it is needed.

Endometriosis affects everyone differently. Symptoms can be mild or severe, intermittent or constant, and can change over time. Someone may be able to work without difficulty much of the time, but need flexibility or adjustments when symptoms flare, or on returning to work following surgery. However, 88% of employees believed workplace policies did not properly account for long-term conditions such as endometriosis.

Too many employers still do not understand endometriosis or the reality of fluctuating long-term health conditions. As a result, employees struggle without support, feel unable to speak openly about their needs, and can find their symptoms treated as a barrier to remaining in work or progressing. Endometriosis can meet the legal definition of disability when symptoms have a substantial and long-term adverse effect on normal day-to-day activities, yet 49% of employees had received no workplace adjustments.

With the right understanding and support, those with endometriosis can remain in work and thrive. Supporting employees with endometriosis does not have to be complicated. The changes required are often straightforward: informed conversations, reasonable adjustments and flexibility when symptoms change. Through Endometriosis UK's Endometriosis Friendly Employer scheme, we have seen work-places getting it right for both their employees and the organisation. Government must now give all employers the guidance they need so that nobody with endometriosis is left behind.

The evidence presented in this inquiry is clear: action is needed now. Too many with endometriosis are struggling to remain in work or leaving employment altogether because the support they need is not there. Employers may want to help but lack the awareness and policy guidance to do so: 79% of employers said current employment law and guidance did not provide sufficient clarity on supporting conditions such as endometriosis, whilst 73% said their organisation would be likely to implement government-backed guidance.

This report must mark a step change in how those with endometriosis are supported in work. We urge policymakers, employers and healthcare services to act on its evidence and recommendations. By working together, we can create workplaces where those with endometriosis are understood, supported, and able to thrive.

On behalf of Endometriosis UK, I'd like to say a heartfelt thank you to the All-Party Parliamentary Group on Endometriosis for launching this important Inquiry into endometriosis in the workplace. Their commitment in ensuring the voices of those with endometriosis are heard in Parliament offers a real opportunity to make a lasting difference.

Continued overleaf

ENDOMETRIOSIS (NOT) IN THE WORKPLACE

Report of the All-Party Parliamentary Group on Endometriosis

We are deeply grateful to everyone who took the time to complete the survey and provide evidence, including those with endometriosis, employers, occupational health professionals, HR experts, patient advocates and healthcare practitioners. Your experiences, expertise, and insights have been invaluable in demonstrating both the barriers faced and the opportunities to create more supportive, inclusive working environments for all those with endometriosis. Thank you.

Emma Cox

CEO of Endometriosis UK



What is endometriosis?

Endometriosis occurs when cells similar to the ones in the lining of the womb (uterus) are found elsewhere in the body.

These cells can grow and change in response to hormones in the menstrual cycle, causing inflammation, pain and scar tissue. Endometriosis is most commonly found on the lining of the pelvis (peritoneum) and may involve the ovaries and other pelvic organs, such as the bowel or bladder. Less commonly, endometriosis can also be found outside the pelvis, such as in the chest.

Types of endometriosis

The cause of endometriosis is unknown and there is no definite cure.

There are four different types of endometriosis, and it is possible to have more than one type. The different types refer to the location, amount and depth of endometrial lesions.

- 1. Peritoneal (superficial) endometriosis** is found mainly on the pelvic peritoneum - a thin film that lines the inner surface of the pelvis and surrounds the pelvic organs.
- 2. Ovarian endometriosis (endometrioma)** is when endometriosis cysts are found in the ovaries.
- 3. Deep endometriosis** is found in locations such as the bladder, bowel and recto-vaginal septum (the tissue separating the vagina and the rectum). The lesions are at a deeper level than peritoneal (superficial) endometriosis.
- 4. Extra-pelvic endometriosis** is when endometriosis is found outside of the pelvis, such as in the thorax (chest) and caesarean scars.

Adenomyosis is a related condition where cells similar to the ones in the lining of the womb grow within the muscle of the womb wall. Like endometriosis, adenomyosis responds to the hormones in the menstrual cycle and affects 10% of women and those assigned female at birth. You can have only endometriosis or adenomyosis, although it is quite common to have both.

Continued overleaf

Symptoms of endometriosis

The classic endometriosis symptoms include:

- Pelvic pain
- Painful periods that interfere with everyday life
- Heavy menstrual bleeding
- Pain during or after sex
- Painful bowel movements/when having a poo
- Pain when urinating/peeing
- Difficulty getting pregnant – up to 70% of those with endometriosis will be able to get pregnant naturally
- Fatigue, with one or more of the above symptoms.

Executive summary

The UK cannot afford to lose people from the workforce just because their health needs are poorly understood or inadequately supported. At a time when ill-health is one of the biggest challenges facing the labour market, helping people to remain in sustainable work is both a social and an economic imperative. Around 2.8 million people are currently economically inactive because of long-term ill-health, while the Government's *Keep Britain Working*¹ review estimates that health-related economic inactivity costs the UK £212 billion each year through lost productivity, increased welfare spending and greater pressure on public services. Endometriosis is a practical test case for the Government's *Keep Britain Working* ambitions.

Endometriosis is a chronic, sometimes debilitating condition affecting women from puberty to menopause, although the impact may be felt for life. Yet the evidence gathered by this All Party Parliamentary Group (APPG) inquiry shows too many are struggling to stay in work while managing severe and sometimes unpredictable symptoms, lengthy waits for diagnosis and treatment, and workplaces that do not always understand the condition or provide the flexibility and adjustments that could help them thrive at work. Some reduce their hours, turn down opportunities or change careers; others leave work altogether. Behind those distressing individual experiences lies a wider cost, whether this is to employers losing skilled and experienced staff, to household incomes and financial security, and ultimately to an economy that needs more people to be able to participate and thrive in work.

The employee survey which forms the basis of much of this report received 6,239 responses. 90% had taken time off because of endometriosis, while 55% had used annual leave instead of sick leave. 47% had lost income and 40% had experienced financial hardship. When asked to consider the previous six months, 36% reported working in severe pain at least several days each week.

These outcomes are not caused by endometriosis alone. Written and oral evidence repeatedly described a mismatch between a chronic, fluctuating and sometimes disabling condition and workplaces organised around predictable attendance, uninterrupted productivity and linear recovery. Women were often expected to adapt themselves to rigid systems rather than being offered support that met their needs.

49% of respondents said endometriosis had made it difficult to progress in their career. 40% had turned down opportunities, 39% had reduced their hours and 28% had left a job. Witnesses described the resulting loss of confidence, professional identity, earnings and pension security. Some moved into insecure work or self-employment simply to gain flexibility.

Support remains inconsistent. 46% of employee respondents had received workplace adjustments. 62% had felt unable to be honest with their line manager, while 94% believed employers lacked a good understanding of endometriosis. The employer survey, completed by 250 respondents, helps explain this gap: 72% said their organisation provided no training or guidance on women's health, and only 16% reported manager training on health conditions to better understand how they could help employees.

¹ <https://www.gov.uk/government/publications/keep-britain-working-review-final-report/keep-britain-working-final-report>

ENDOMETRIOSIS (NOT) IN THE WORKPLACE

Report of the All-Party Parliamentary Group on Endometriosis



Employers were clear that they wanted more help. 79% said current employment law and guidance did not provide sufficient clarity on supporting conditions such as endometriosis. 94% said a model endometriosis action plan would be helpful, and 73% said their organisation would be likely to implement government-backed guidance. This is a strong mandate for practical national action, not simply further awareness-raising.

The inquiry heard that a formal diagnosis should not be required as a precondition to receiving support in the workplace. Long diagnostic delays mean many experience serious symptoms for years without formal confirmation. Workplace decisions should be based on the functional impact of symptoms and need, not on whether an employee has completed a lengthy diagnostic process.

Absence management emerged as a particular source of harm. 52% said workplace absence policies had caused difficulties. Among those answering the relevant question, 76% had felt pressure to return before they were ready and 36% had faced a formal discussion linked to absence caused by the condition. Financial pressure, inadequate sick pay and fear of trigger points drove women to work while unwell or return too soon after surgery.

Practical adjustments can make a decisive difference. Flexible hours, home or hybrid working where possible, changes to duties, flexibility to change shifts, additional breaks, suitable uniforms, immediate toilet access, phased returns and paid time for medical appointments can help workers to remain productive. Support must work for staff in transport, care, retail, healthcare, manufacturing, security (e.g. the police) and other roles where working from home is impossible.

The central finding of this inquiry is clear: women with endometriosis should not have to sacrifice their health, income or career because workplaces fail to understand or accommodate a long-term fluctuating condition. Government, employers, employment bodies and health services must act together to make support consistent, accessible and enforceable.

What employees told us

- **6,239** women with confirmed **(85%)** or suspected **(15%)** endometriosis responded to the employee survey.
- **97%** had worked while experiencing severe pain because of endometriosis.
- **91%** had taken time off work because of the condition.
- **76%** said endometriosis reduced their productivity.
- **73%** needed time off at short notice.
- **62%** had worried about losing their job.
- **55%** had used annual leave instead of sick leave.
- **49%** had experienced difficulty progressing their career.
- **47%** had lost income and **39%** had experienced financial hardship.
- **40%** had turned down career opportunities; **39%** had reduced their hours; **28%** had left a job.
- **49%** had not received workplace adjustments.
- **62%** had felt unable to be honest with their line manager.
- **52%** said workplace absence policies had caused difficulties.
- **76%** of those answering the question had felt pressure to return before they were ready after a period of endometriosis related absence.
- **36%** had faced a formal discussion linked to absence caused by endometriosis.
- **88%** believed workplace policies did not properly account for long-term conditions such as endometriosis.
- **94%** believed employers did not have a good understanding of endometriosis.

What employers told us

- **250** employers, managers and organisational representatives responded to the employer survey.
- **72%** said their organisation provided no training or guidance on women's health.
- Only **16%** reported manager training on health conditions.
- Just **11%** reported a menstrual health policy.
- Only **45%** said their absence policies allowed flexibility for long-term fluctuating conditions.
- **79%** said current employment law and guidance did not provide sufficient clarity on supporting conditions such as endometriosis.
- **94%** said a model endometriosis action plan would be helpful, and **73%** said their organisation would be likely to implement government-backed guidance.
- **80%** supported explicit recognition in employment guidance that the effects of endometriosis may meet the Equality Act definition of disability.

About the inquiry

The APPG on Endometriosis established this inquiry to examine the experiences of women with diagnosed or suspected endometriosis in the workplace and to identify practical changes that would help them remain and progress in employment.

The inquiry drew on employee and employer surveys, oral evidence sessions and written submissions from women with lived experience, researchers, healthcare practitioners, employers and advocates. The employee survey received 6,239 responses. Of these, 4,249 said their endometriosis had been confirmed through surgery and a further 1,072 had been told by a doctor that they had the condition. Others were awaiting investigation, appointments or surgery. The survey ran from May 2026 until July 2026 and four oral evidence sessions were held between May and September.

Most respondents were in paid work: 68% worked full time and 18% part time. 6% said they were unable to work because of their health. 51% worked, or had most recently worked, in the public sector; 34% in the private sector; and 6% in the charitable or voluntary sector.

The employer survey received 250 responses. Respondents included people working in HR, senior leadership and line management, and represented organisations of different sizes: 24% had fewer than 50 employees and 26% had more than 5,000. 46% worked in the public sector, 41% in the private sector and 7% in the charitable or voluntary sector.

Both surveys were self-selecting and should not be treated as representative of all those with endometriosis nor all UK employers. The employer sample is likely to over-represent organisations and individuals already engaged with the issue. Response numbers are reduced at later questions, so percentages in this report use the number answering each question. Percentages relate to the number of respondents who answered the relevant question, and some questions allowed more than one response. The oral-session summaries were produced from automated transcripts and have been used to identify themes rather than to support verbatim quotations or uncertain attribution.

Endometriosis UK, which provides the secretariat to the APPG, provided administrative support for the inquiry. Endometriosis UK also commissioned and funded Pulse Consultancy to support the APPG with the drafting of this report.

A note on language and inclusion

Endometriosis can affect women, trans men and some non-binary people. In this report, references to “women” are intended to include all people assigned female at birth who may be affected by endometriosis. We recognise that people’s experiences of the condition are shaped by a range of factors, including age, ethnicity, disability, gender identity, sexuality, occupation, income and employment status, and that no single experience is representative of everyone with endometriosis.

Endometriosis and working life

Endometriosis affects women very differently. Many with the condition are able to work without significant difficulty or with relatively modest adjustments. This inquiry focused particularly on those who have experienced barriers at work, and its findings should not be read as suggesting that everyone with endometriosis will need substantial time away from work or require extensive support.

Those affected may face repeated GP and hospital appointments due to symptoms that may be cyclical, persistent or unpredictable. The effects can include disturbed sleep, cognitive difficulty and mental distress. Management of endometriosis, such as hormonal medication, can help. The only treatment is surgery, with the associated potentially lengthy recovery time. This works for some women, although it does not guarantee immediate or permanent relief from symptoms, and it can be recurring.

The varying and fluctuating impact does not fit neatly within workplace systems designed around one-off or short, predictable episodes of illness. Written evidence described women undertaking extensive hidden activities simply to remain at work: monitoring symptoms, planning routes around toilet access, carrying medication and spare clothes, rearranging tasks, compensating for lost productivity and concealing symptoms to avoid stigma.

Diagnostic delay compounds the problem. Several contributors described living with severe symptoms for years without formal confirmation. Some employers treated diagnosis as proof that was required before support could be considered. Based on evidence from women with lived experience, clinicians and government, the inquiry is adamant that adjustments should be based on the impact of symptoms and the barriers a person faces at work, not solely on a diagnostic label. This is consistent with the direction of the Keep Britain Working Review, which calls for earlier workplace intervention, better support for employees and line managers, and practical stay-in-work plans before health problems escalate into prolonged absence or labour-market exit.

The relationship between healthcare and employment also matters. Long waits, fragmented care and repeated appointments can worsen symptoms and destabilise employment. The burden of coordinating communication between clinicians, occupational health and employers often falls on the person who is already unwell.

The need to prevent avoidable labour-market exclusion starts before someone has established a career. At a time when more than one million young people are not in education, employment or training, the inquiry also heard that severe and poorly supported symptoms can affect education, examinations and the transition into employment, with some young women losing confidence in their ability to progress. This reinforces the importance of early diagnosis, appropriate support in education and smooth transitions into employment.



The impact of endometriosis at work

Working through pain and fatigue

“ I have had times at work where I have been sick, passed out and been in so much agony but was told I needed to try and carry on through the day. I work in a hospital and it still isn’t spoken about enough. ”

Of the 6,199 respondents who answered the question 97% said they had worked while experiencing severe pain because of endometriosis. Fatigue was reported by 97% of respondents to the relevant question, increased stress or anxiety by 86%, reduced productivity by 76% and difficulty completing particular tasks by 59%.

“ During my working career I have repeatedly hidden the severity of my symptoms in case I got fired or disciplined, made light of them, pushed through when I shouldn’t have. I am a trainer and would feel the pain and shame while training, wearing pads and tampons but still flooding or being doubled over and having to sit down while training. ”

This presenteeism was a central theme across the evidence. Respondents described working through severe pain, nausea, heavy menstrual bleeding, bowel symptoms, exhaustion and cognitive fog because they could not afford to stop, feared absence triggers or did not want to let colleagues down. Researchers warned that the impact of presenteeism on safety, performance and long-term health is largely unmeasured.

Contributors also described the depletion that follows. Using all available energy to remain at work left little capacity for recovery, family life, exercise or basic daily activities. For some, repeatedly pushing through symptoms contributed to deterioration and longer periods of absence.

Absence, annual leave and recovery

“ My employer offers flexible working and I’m largely home based which has made all the difference. ”

90% of respondents had taken time off because of endometriosis, and 73% said they had needed time off at short notice. 55% had used annual leave instead of sick leave. These findings reflect the experiences of a self-selecting group of respondents and should not be taken to mean that everyone with endometriosis will experience frequent or prolonged absence. For many women, relatively modest adjustments and greater flexibility can help them remain at work and manage symptoms more effectively.

Where absence was needed, respondents described a range of pressures affecting how they managed it. Some used annual leave because they feared disciplinary action, could not afford reduced pay, felt uncomfortable explaining intimate symptoms, or believed annual leave would be viewed more favourably. Others described returning before they felt ready after surgery because of financial pressure or concerns about promotion and job security.

The evidence also highlighted the value of flexibility. In some cases, a later start, a short period away from work, temporary home working where the role allowed, or an adjustment to duties could help someone continue working without needing a full day's absence. This underlines the importance of avoiding overly rigid systems and of discussing what support is practically achievable for both the employee and the employer.

Recovery can also vary considerably. A phased return may be appropriate following surgery, but support may need to be reviewed as symptoms change or treatment progresses. The aim should be a proportionate, individual approach that helps women recover well, remain in work where possible and return sustainably when time away is needed.

Careers constrained and identities eroded

“ I had to leave my job, I was unable to attend a lot and if I was I felt severely unwell and it affected my productivity. I was going to do an apprenticeship with the NHS but could no longer support myself on my reduced hours and salary- as well as physically so I had to move back to my mum's house. ”

49% of respondents said endometriosis had made it difficult to progress in their career. 40% had turned down opportunities, 39% had reduced their hours, 29% had changed jobs and 28% had left a job.

Written evidence described women declining promotion, training or travel because they could not predict their symptoms. Some sought roles below their experience or moved into part-time, insecure or self-employed work to obtain flexibility. Others accumulated short periods of employment after repeated ill health or poor treatment, making it harder to secure their next role.

“ I've had to leave my previous job, I'm unable to use my degree as the field requires volunteer/training hours and largely physically demanding. ”

The loss was not only financial. Contributors described a gradual erosion of professional identity and confidence as they repeatedly renegotiated what they could reliably deliver. High-performing employees felt reduced to an absence record or a health problem rather than valued for their skills and contribution.

“ I wish I never had to leave my dream job. I stepped away due to severe symptoms and pain that occurred outside of my period. I felt ashamed when I left because I knew I’d lose my identity and my financial means. ”

Financial insecurity

47% had lost income and 39% had experienced financial hardship. Reduced hours, unpaid leave, inadequate sick pay and labour-market exit all contributed. For workers without occupational sick pay, including many self-employed and lower-paid workers, there may be no realistic option to stop working during a flare.

“ When I’m off work on sick I lose my shift pay which is a 36% uplift. It’s simply too much of a financial loss to stay off work for the amount of time I actually need. ”

Witnesses described falling behind on bills, risking debt and returning too early after surgery.

“ In my previous job , I had to take time off to have my laparoscopy, and because I was zero hours I wasn’t getting paid or sick leave so I felt I had to recover quicker to make up my hours that I lost for financial reasons. ”

Financial stress can itself worsen pain and mental distress. The consequences can also persist through lower pension contributions, reduced savings and long-term damage to earning capacity.

Some evidence highlighted additional vulnerability for those whose employment is tied to immigration status, as well as for workers in insecure contracts or probation periods.

Fear of losing both employment and wider security can make disclosure or absence feel impossible.

Disclosure challenges, lack of understanding and unsupportive workplace culture

62% had felt unable to be honest with their line manager about their medical condition. Respondents described embarrassment about discussing heavy menstrual bleeding, bowel and bladder symptoms, fertility or pain. Others feared being perceived as unreliable, weak or less committed.

Written and oral evidence showed that these fears were often grounded in experience. Contributors reported intimate medical information being discussed openly, symptoms being compared with normal periods, inappropriate comments about fertility, repeated demands to justify illness and assumptions that surgery should have cured the condition.

ENDOMETRIOSIS (NOT) IN THE WORKPLACE

Report of the All-Party Parliamentary Group on Endometriosis

Support was frequently described as a “line manager lottery”. Research submitted to the inquiry found that only 23% of respondents in one NHS workforce study felt their manager knew how to support them. The fact that poor understanding was reported even in health and public-sector organisations shows that policy commitments do not automatically translate into practice.

Managers do not need to become clinicians. They do need to listen, protect confidentiality, understand the organisation’s responsibilities and focus on the barriers preventing an employee from working safely and effectively. The employer survey suggests a gap between personal confidence and organisational capability: while 66% felt confident supporting an employee with endometriosis, only 16% reported manager training on health conditions. Employees should not have to educate each new manager from first principles.

Peer networks and workplace champions can help create openness, but voluntary initiatives are fragile without senior sponsorship. Cultural change requires leadership, resources, clear accountability and the integration of endometriosis and menstrual health into ordinary management systems.



Support, adjustments and fair treatment

What employers told us

The employer survey shows that some employers are willing to act to support their employees. 62% of respondents had supported an employee with endometriosis, and many free-text responses showed a genuine desire to retain staff and respond compassionately. Employers described flexible working, adapted absence monitoring, occupational health, employee assistance programmes and individual support plans as useful tools.

At the same time, provision was patchy. 72% reported flexible-working policies and 64% occupational-health support, but only 41% reported specific support for long-term conditions, 16% manager training on health conditions and 11% a menstrual health policy. 11% said none of the listed measures were in place.

Employers identified practical tensions that must be addressed. These included managing unpredictable absence in small teams, maintaining services in customer-facing or safety-critical roles, deciding what adjustments are reasonable, supporting recovery after surgery and handling difficult conversations about whether a role remains sustainable. These are not arguments against support. They demonstrate why employers need clear processes, examples and access to advice.

Only 45% said their absence policies allowed flexibility for long-term fluctuating conditions. This means employees in these organisations cannot draw upon supportive policies which may help them to stay in work.

Adjustments must be individual and practical

“ It’s made going into the office quite hard because I need to be comfortable during a flare up i.e. close to a toilet, not wearing restrictive clothing that a formal office requires, and need to be able to take breaks / lay down sometimes when feeling chronically tired. ”

49% of employee respondents had not received workplace adjustments. Yet many practical measures which would help were identified: time off for medical appointments, flexible hours, remote or hybrid working where suitable, additional breaks, temporary reductions in hours, modified duties, rest facilities and ready access to toilets. Employer responses broadly supported this approach but also showed that organisations need clearer guidance on the range of possible adjustments and how to judge what is reasonable in different roles.

Commuting is a distinct barrier for some. Someone may be capable of carrying out their role from home but unable to tolerate a long journey, standing on public transport. Adjustments could include agreeing start and finish times that allow for commuting outside of rush hour.

“ My employer allows me to leave work early to avoid the rush hour commute - meaning that I can work later into the evening to make up the time. When I have a flare up, I can work from home, which helps me to stay in work. ”

By contrast, reimposing blanket office-attendance rules, especially with rigid times to be present, can remove an adjustment that previously enabled someone to work.

Support must also work beyond offices. Evidence from hairdressing, domiciliary care, rail and other location-based roles highlighted the need for clean and private toilets, suitable uniforms and PPE, predictable breaks, modified shift patterns and temporary changes to physically demanding duties. Remote working is valuable but cannot be the default answer for every occupation.

Adjustments should be recorded and reviewed. A workplace health passport is a simple record of agreed adjustments that can follow an employee between managers or roles, reducing repeated disclosure and helping support remain consistent. It should be controlled by the employee and should not become an additional evidential hurdle.

“ With the right support in a workplace, I’m completely able to carry out my job. ”

Absence policies designed for acute illness

52% of employee respondents said their workplace absence policy had caused difficulties. The employer survey showed why this remains a systemic problem: only 45% said their policies allowed flexibility for long-term fluctuating conditions. Employers should ensure absence trigger systems (which prompt formal action after a set number or pattern of absences) take proper account of disability-related and medically evidenced recurrent absence. There is the danger that trigger systems can penalise recurrent short absences more heavily than one continuous period, despite intermittent absence being an expected feature of many fluctuating conditions.

76% felt pressure to return before they were ready, while 36% had faced a formal disciplinary or performance-related discussion linked to endometriosis absence.

“ Taking sick leave every month for pain put me into absence monitoring and made me feel I had to go into work when not well enough. ”

Some contributors described capability or performance procedures being used despite strong performance or occupational-health advice.

Employers must retain the ability to manage attendance fairly. But long-term or potentially disability-related absence should be considered in context, with adjustments to trigger points and proper attention to medical evidence. Performance, promotion and redundancy decisions should not penalise employees for requesting support.

Occupational health and vocational support

Only 21% of respondents had received occupational-health support. This has the potential to help translate symptoms into practical recommendations, giving managers confidence to act. However, there were also examples where recommendations were ignored, applied temporarily or based on limited knowledge of endometriosis.

The inquiry received evidence supporting a stronger role for vocational rehabilitation (practical support to help people remain in work or return to work after illness, treatment or surgery) and occupational therapy. Functional assessment can connect symptoms to specific job tasks, advise on pacing and energy management, support phased returns, and bridge the gap between healthcare and employment. This merits testing within women's health services and emerging endometriosis pathways.

Occupational-health recommendations should carry meaningful weight. Where an employer does not implement a medically supported adjustment, it should be able to explain clearly and evidence why it is not reasonable or operationally possible.

Equality and disability

61% of respondents considered themselves disabled because of endometriosis, and a further 24% were unsure. Only 5% said their adjustments had been formally recorded as disability-related.

Under the Equality Act 2010, legal protection depends on the effect of the condition: whether it has a substantial and long-term adverse impact on normal day-to-day activities. Endometriosis can meet this test, but it is not automatically a disability in every case.

The inquiry heard widespread confusion about this position. Some employees believed a named diagnosis was essential; some employers appeared to treat endometriosis as outside disability law; and many lacked the time, money or health to challenge poor practice. 93% of survey respondents believed endometriosis should be explicitly recognised in employment guidance as a condition that may meet the definition of disability.

The immediate priority should be to update statutory and practical guidance so that endometriosis and other menstrual health conditions are clearly included as examples of impairments, and that may have fluctuating or recurring effects. Where the functional impact is evident, guidance should recognise that support can be appropriate without a diagnosis.

This should be accompanied by accessible enforcement and advice. Rights that exist only on paper do not protect employees who cannot navigate a lengthy legal dispute while managing serious illness.

Unequal experiences

Experiences of endometriosis at work are not uniform. Written evidence highlighted how race, disability, sexuality, socioeconomic status, occupation, seniority and employment type can compound disadvantage. Those in lower-paid, insecure or public-facing roles often have less autonomy and fewer adjustment options.

Contributors from ethnic minority backgrounds described particularly long diagnostic journeys and experiences of not being listened to by health professionals. Self-employed workers may have no sick pay or organisational support. Women in probation periods may avoid disclosure entirely. Those in male-dominated industries can face unsuitable facilities and uniforms, while care and transport workers, to name just two sectors, may not have reliable access to a toilet.

The evidence base is not yet sufficient to quantify each disparity. Future research and employer data should therefore examine outcomes by ethnicity, disability, occupation, contract type, income, age and other relevant characteristics, with care taken to protect confidentiality.

What good support looks like

Good support begins with belief, dignity and an early conversation. The strongest examples involved managers who listened, focused on practical barriers and accepted that needs could change over time.

Effective support will vary significantly depending on the individual's symptoms and the nature of their role. It may include flexible start and finish times, home or hybrid working where the role allows, additional breaks, time for appointments, temporary or longer-term changes to duties (as well as shifts, uniforms or working location), phased returns, ready access to toilets and rest facilities and agreed adjustments recorded so they do not have to be repeatedly renegotiated.

Good organisations embedded menstrual health including endometriosis within existing systems rather than relying on a single awareness day or an isolated policy. They trained managers, involved occupational health and HR, supported staff networks and secured visible senior leadership. The employer evidence suggests that a coherent framework may be more useful than requiring every organisation to create a lengthy standalone policy, provided endometriosis remains explicitly visible and the framework produces clear entitlements and consistent practice.

ENDOMETRIOSIS (NOT) IN THE WORKPLACE

Report of the All-Party Parliamentary Group on Endometriosis

The appetite for such support is clear. 79% of employers said current law and guidance lacked sufficient clarity. 94% would find a model action plan helpful, and nearly three-quarters said their organisation would be likely to implement guidance provided by government.

There are also encouraging examples of employers taking practical steps to get this right. Endometriosis UK's Endometriosis Friendly Employer Scheme is already helping organisations improve understanding, support managers and create workplaces where employees feel more confident asking for help.

“ Since becoming an endometriosis friendly employer (through Endometriosis UK's Employment Scheme) I've been surprised at how simple the support and interventions for sufferers are, which is great. ”

The inquiry also heard about the value of existing standards, including BS 30416 and the newer ISO 45010 framework on menstruation, menstrual health and menopause, which give employers practical guidance on issues such as workplace adjustments, line-management conversations and organisational culture.



These examples show that positive change is achievable. In many cases, what makes the biggest difference is not an expensive new programme, but a combination of informed managers, clear policies, flexibility and a willingness to listen. Where that support is in place, women with endometriosis can remain in work, progress in their careers and contribute fully. The challenge is to make that kind of good practice more consistent across workplaces of all sizes and sectors.

The contrast between positive and negative experiences shows that poor outcomes are not inevitable. Often the decisive difference was not an expensive intervention, but whether the organisation responded early, flexibly and consistently.

Devolution and implementation across the UK

The APPG's ambition is that everyone with endometriosis should benefit from consistent standards of workplace support wherever they live or work in the UK.

Employment rights and equality law are largely reserved to the UK Parliament in relation to England, Scotland and Wales, while employment law and equality legislation are devolved in Northern Ireland. Health services and many aspects of health policy are devolved across the UK. The recommendations below therefore identify the UK Government where action falls within its responsibilities, with equivalent action sought from the devolved governments and relevant bodies where responsibility is devolved.



Recommendations

1. Embed a national framework for endometriosis and menstrual health at work

The UK Government should work with people with lived experience, employers, trade unions, ACAS, the Labour Relations Agency in Northern Ireland, equality bodies, charities, professional bodies and the devolved governments to embed a consistent workplace framework for endometriosis, menstrual health and long-term fluctuating conditions.

This should build on existing standards and good practice, including ISO 45010* and the new Government Menopause Employer Action Plans, and set clear practical expectations around reasonable adjustments, absence management, flexible working, medical appointments, workplace facilities and support for managers, with proportionate resources for smaller employers.

The employer survey provides a strong mandate: 94% said a model action plan would be helpful and 73% said they would be likely to implement government-backed guidance.

2. Clarify equality and employment guidance for fluctuating conditions

The UK Government and Equality and Human Rights Commission should review and update Equality Act and employment guidance applying in Great Britain to ensure it clearly reflects the realities of chronic and fluctuating conditions such as endometriosis. Guidance should make clear that legal protection depends on the substantial and long-term impact of symptoms, rather than diagnosis alone, and should explain how recurring or intermittent effects should be considered.

ACAS guidance should similarly provide practical advice on reasonable adjustments, confidentiality, support without a confirmed diagnosis and the fair handling of short, intermittent absences.

Equivalent clarification should be considered within Northern Ireland's equality and employment framework.

3. Review Statutory Sick Pay and medical leave

The UK Government should review whether Statutory Sick Pay adequately supports people with fluctuating long-term conditions, including where absence may be recurrent and short term.

In Great Britain, it should also consider a right to reasonable paid time for significant medical appointments, treatment and recovery, with equivalent provision considered in Northern Ireland.

* ISO 45010:2026 is an international occupational health and safety guidance standard focused on supporting menstruation and menopause in the workplace, published in September 2026. It provides practical recommendations for workplace policies, facilities, and supportive cultures to help organisations create inclusive environments.

4. Require fair absence and capability processes

Employers should review trigger points, scoring systems and capability procedures so that disability-related or medically evidenced recurrent absence is considered in context.

Automated absence-management or trigger systems should not lead directly to disciplinary or capability action without individual review. Employees should not be disadvantaged in performance, promotion, redundancy or dismissal decisions because they have requested or used adjustments.

5. Design support for all workplaces

Guidance must address non-office roles, including toilet access, breaks, uniforms and PPE, shift patterns, commuting, physical duties and return-to-work arrangements. Employers should assess the equality impact of blanket attendance or return-to-office requirements.

6. Ensure support is inclusive and accessible to all

Government guidance, workplace standards and employer practice should be designed to work for people across different backgrounds, occupations and employment circumstances. This should include people in lower-paid, insecure, self-employed and non-office work, disabled people, people from ethnic minority backgrounds, and those whose immigration status or caring responsibilities may affect their ability to access support.

Guidance, standards, training and evaluation should be co-produced with people with endometriosis who reflect this diversity of experience, so that support is practical, equitable and does not depend on employees having high levels of workplace autonomy, confidence or access to specialist HR and occupational-health support.

7. Equip managers to support employees effectively

The UK Government should work with ACAS, employers, trade unions and relevant organisations to provide free, practical resources for line managers on supporting people with endometriosis, menstrual health conditions and other fluctuating long-term conditions. These should cover supportive conversations, confidentiality, reasonable adjustments, absence, treatment and recovery, and signposting to further help. Larger employers should be encouraged to incorporate this into routine management and HR training.

8. Make adjustments clear, recorded and portable

Governments and relevant employment bodies across the UK should develop a simple workplace health-passport template (so that employees need only tell their stories once): a record of agreed adjustments and support that can, with the employee's consent, follow them between managers, teams or roles.

Employers should offer written adjustment agreements where appropriate, subject to regular review, reducing the need for employees to repeatedly disclose their condition or renegotiate the same support.

9. Support SMEs with practical resources

Governments and relevant employment bodies across the UK should provide a concise toolkit for smaller employers: a short condition guide, examples of low-cost adjustments across different job types, template conversations and adjustment records, guidance on absence and confidentiality, worked examples of reasonable operational decisions, and routes to specialist advice.

Resources should be usable by employers without dedicated HR or occupational-health capacity.

10. Strengthen occupational and vocational support

DHSC and NHS England (and the future combined organisation) should test and evaluate occupational-therapy and vocational-rehabilitation support (including help to stay in work, return after treatment or surgery, and agree on practical workplace adjustments) within women's health services, neighbourhood services and endometriosis pathways in England.

The Scottish Government, Welsh Government and Northern Ireland Executive should consider equivalent approaches within their respective health systems.

Employers should give proper weight to occupational-health recommendations and, where a recommended adjustment is not implemented, should clearly explain why it is not reasonable or operationally practicable.

11. Improve data and accountability

The UK Government, working with devolved governments and relevant public bodies, should improve evidence on the impact of endometriosis on the gender pay gap and pay progression, working patterns, absence and labour-market exit, including inequalities by ethnicity and other relevant characteristics.

It should also track employer awareness, policy coverage and implementation of national guidance. Larger employers should be encouraged to examine retention and progression as part of gender-equality and workforce-health strategies.

12. Connect healthcare and employment policy

Health services across all four nations should recognise employment as an important health outcome. DHSC and NHS England (and the future combined organisation), working with equivalent bodies in Scotland, Wales and Northern Ireland, should ensure that women with endometriosis receive practical advice on work, fit notes and functional impact during diagnosis, treatment and recovery. Earlier diagnosis and timely access to appropriate care are essential to preventing avoidable job loss.



All Party Parliamentary Group

Endometriosis

Acknowledgements

APPG Membership:

Chair – Kirsteen Sullivan MP

Deputy Chair – Sir Alec Shelbrooke MP

Officer – Gill Furniss MP

Officer – Rachel Taylor MP

Secretariat – Endometriosis UK

A huge thank you to all the Members of the APPG on Endometriosis, and all who contributed to the Inquiry through the survey, hearings and submitting evidence.

Endometriosis UK acts as the group's secretariat. Endometriosis UK commissioned Pulse Consultancy to support this report.

