

Endometriosis: 'I feel like I'm screaming into the void.'

March 2026

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Photo: Women's
Health Hope
Award Winning
Campaign 'The
Painathon'
(2025)

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1.0 Introduction

1.1 Healthwatch Essex

Healthwatch Essex is an independent charity which gathers and represents views about health and social care services in Essex. Our aim is to influence decision makers so that services are fit for purpose, effective and accessible, ultimately improving service user experience. We also provide an information service to help people access, understand, and navigate the health and social care system. One of the functions of a local Healthwatch under the Health and Social Care Act 2012, is the provision of an advice and information service to the public about accessing health and social care services and choice in relation to aspects of those services. This document was revised in July 2022 and the role of Healthwatch was further strengthened as a voice of the public with a role in ensuring lived experience was heard at the highest level.

In June 2025, as part of the Dash Review, the Government announced its intention to close the Healthwatch network. However, Healthwatch Essex is an independent charity, and the organisation is currently re-branding. We have developed a sustainable model that will protect the independence of patient voice into the future.

The Healthwatch Essex Information and Guidance team are dedicated to capturing the health and social care experiences people in Essex are meeting daily. The team responds to enquiries relating to health and social care and are equipped through training, to offer specific information to the public or other professionals. The team are well placed to listen, reflect on and support people to share complex experiences such as those shared in this report. You can find details of how to contact our team on our website here - <https://healthwatchessex.org.uk/speak-to-our-team/>.

1.2 Background

I attended an endometriosis support group in south Essex and was inspired by the women there and the experiences they were going through. We felt strongly as a team that this condition needed to be highlighted to the public and health professionals/organisations for improved understanding and knowledge as well as improving peer support for these women.

Endometriosis UK recently released a report that highlighted the increase in diagnosis times for endometriosis. In an article they said:

'New data released by Endometriosis UK has revealed that the average time to receive a diagnosis of endometriosis in the UK has now reached nine years and four months. Alarmingly, this figure has increased from an average of eight years reported in 2020. This rises to eleven years for individuals from ethnically diverse communities.'

The findings, from a survey by Endometriosis UK, highlight the struggles of individuals seeking diagnosis and management to help reduce the severity of symptoms: 39% of respondents reported needing to visit their GP ten times or more before endometriosis was suspected. Additionally, 55% of respondents attended A&E with their symptoms, but 46% of these were sent home without treatment.'

You can read the article here: [Endometriosis UK release new report highlighting alarming increase in endometriosis diagnosis times | Endometriosis UK](#). You can also access their full report here: [Endometriosis - The State of Endometriosis Care Report.pdf](#).

1.3 Acknowledgements

Healthwatch Essex would like to thank all the women who took part in this project through the survey, podcast, interviews and attending the support

groups. Our thanks are made to those individuals who took the time to meet with us and share their personal, heartfelt and emotive stories.

1.4 Terminology

Adenomyosis - a condition where the lining of the womb (uterus) starts growing into the muscle in the wall of the womb.

Endometriosis - Endometriosis is a condition where endometrial tissue, similar to the lining of the uterus, grows in other places, such as the ovaries and fallopian tubes. Common symptoms include chronic pelvic pain, fatigue, heavy menstrual bleeding, pain during or after sex, painful urination and bowel movements, and reduced fertility. Endometriosis usually affects women during their reproductive years but can affect women of any age.

IBS - irritable bowel syndrome.

Laparoscopy - a type of keyhole surgery used to diagnose and treat conditions. It allows a surgeon to use only small cuts and a camera for procedures inside the tummy or pelvis.

MRI - An MRI scan takes detailed pictures of the inside of your body.

PCN - Primary Care Network.

PCSO - Polycystic ovary syndrome.

Ryego - Symptomatic treatment of endometriosis in women with a history of previous medical or surgical treatment for their endometriosis.

UCLH - University College London Hospital.

1.5 Disclaimer

Please note that this report relates to findings and observations carried out on specific dates and times, representing the views of those who contributed. This report summarises themes from the responses collected and puts forward recommendations based on the experiences shared with Healthwatch Essex during this time.

2.0 Purpose

The aim of this project was to canvass lived experiences of the Essex population around endometriosis and analyse this data in relation to current and future service provision. Women had also contacted our Information and Guidance service looking for support with accessing local advice/support for this condition and to be able to give their feedback/experiences with trying to access medical treatment/diagnosis.

Ethical Approval was applied for this project from the Essex County Council Research & Citizen Insight/Policy Unit. The research proposal was approved under the terms of the Essex County Council's research governance guidelines in November 2025.

Gynaecological department waiting times in Essex as of March 2026:

Currently Colchester Hospital is the only centre of excellence in Essex; this means that referrals can come from all over the region and not just Essex, which has a huge impact on waiting times. You can find centres of excellence here: [Find BSGE Accredited Endometriosis Centres in the UK](#)

East Suffolk and North Essex NHS Foundation Trust's (ESNEFT) average waiting time is 40 weeks for a first Gynaecology Endometriosis appointment, which you can see here: [Estimated-waiting-times-March-2026.pdf](#)

ESNEFT's waiting times were discussed in an article for the Ipswich newsletter: 'ESNEFT explains that complex endometriosis cases are referred to Colchester Hospital as a specialist, tertiary centre – one of the only providers in the region to provide this service. The Trust states that current waiting times average 44 weeks for general gynaecology appointments and 49 weeks for specialist endometriosis referrals, though these are estimates and individual cases may differ based on clinical prioritisation

and complexity.' You can read more here: [Forty failed women and counting: Breaking the silence on endometriosis in Suffolk](#)

Both Princess Alexandra Hospital and Mid and South Essex NHS trusts state at least a 22-week waiting time for gynaecology appointments (correct as of March 2026). You can view Princess Alexandra Hospital waiting times here: [The Princess Alexandra Hospital NHS Trust - My Planned Care NHS](#). You can view Mid and South Essex NHS Foundation Trust waiting times here: [Mid and South Essex NHS Foundation Trust - My Planned Care NHS](#).

2.1 Engagement methods

The Survey:

A survey was created to gain perspective and insight from residents who have had experiences of endometriosis and its symptoms. The survey was shared with all our stakeholders/partners. It was promoted across our social media platforms.

One-to-one Interviews:

To further understand the experience of individuals with this condition on an in-depth basis. These interviews were carried out online, via the telephone and in person.

Podcast:

Three members of the Rayleigh endometriosis support group took part in a podcast for our Hidden Voices series to talk about their experiences. The podcast is titled: 'It's not just a bad period!' Living with Endometriosis. You can listen to the episode here: [Hidden Voices • A podcast on Spotify for Creators](#).

Support Groups:

I attended the Rayleigh and North Essex in person support groups. This gave me the opportunity to share details of the project and our aims for it.

2.2 The Survey

The survey consisted of 11 questions and was devised to encompass as many aspects of endometriosis as possible. The survey was primarily in an online format but was also available to be printed off and filled out manually as needed. The Information and Guidance Team at Healthwatch Essex were also available if the survey needed to be completed in any other format, such as over the telephone.

136 women completed the survey.

The questions, and responses received, were as follows.

When did you first start to experience symptoms of endometriosis?

Many women stated that their symptoms started when their periods did; the youngest age for this was nine years old. For others it was after giving birth to their children. Many of the women thought that the pain and heaviness of their periods was 'normal'; there was little to no knowledge or information given to them as to what was classed as 'normal' for a period. This highlights the need for improved education for young women so they can identify any potential problems earlier and seek medical advice.

'From the age of 13, however I just thought that everyone felt the kind of pain I was in and the heaviness of my periods was normal.'

'From the age of around 21 years old but was often put down to different things and not properly explored.'

'From a young age when my periods started, they would always be painful and heavy, but this would be the "normal" thing for women so I got on as best as I could, it got worse over the year and eventually became unbearable in 2024.'

'I think my periods were always pretty bad from when I started having them - potentially more painful than the usual period (not that I would have known that.) So, it possibly started from the age of 13, however, it wasn't

until I was 17 that I really knew something wasn't right and started going to the GP for advice.'

'I started experiencing horrendous pain during my period at the end of primary school. Everyone dismissed it as just normal pains and that I was thin skinned.'

'Heavy periods and pain as a teenager and worse after having my son five years ago.'

'From the age of 13, however I just thought that everyone felt the kind of pain I was in and the heaviness of my periods was normal.'

'This is going to sound weird, but I think I was having symptoms my entire life. I would often have frequent stomach upsets and suffer from constipation a lot as a child. Approaching menarche, this got steadily worse, and then, when my period started, I was floored by bad cramps and heavy bleeding, often suffering frequent bouts of nausea throughout my cycle. Over time, these symptoms have progressed and become steadily worse.'

'Experienced symptoms as young as 14 but was told it was IBS and put on the contraceptive pill from a young age to try to 'balance' my periods.'

'I have struggled with painful periods since they started when I was 10, I first went to the doctors when I was 12.'

'After the birth of my third child, something had changed in my body, he was born in 2012, and I got my official diagnosis in 2024.'

'When I was 13, I'm now 33. It took me eighteen years to get any help, and any diagnosis.'

'Looking back, I can see that my symptoms started from onset of my periods at 11 years. My periods were always extremely heavy and painful.'

'Official symptoms of endo? I'm unsure. But from the very start of my periods at 16, life was hell.'

'This year, I'd been on the contraceptive injection for years but was told I could no longer be on it. Had sterilisation surgery where they found endo, had no follow up regarding this after the surgery and was no longer on the injection. Had a major flare up where the pain was excruciating so went back to the doctors who immediately put me back on the injection!!'

'In 2018 I recognised the symptoms fully but since I started my periods at age 15, I had them without knowing.'

'I first started to experience symptoms when I started my period at 16. I had always suffered horrendous, irregular periods, but had been told this was normal, even though I wasn't able to go to school or get out of bed some months. It wasn't until I was 20 and had an ectopic pregnancy that I was told about endometriosis.'

'I was unaware of endometriosis before diagnosis. But looking back my journey begun around 20 years ago, and it's taken 18 years to get to a place where I am relatively well.'

'I've always suffered with heavy, painful periods, so probably around 2010.'

'I didn't know I had it. I was diagnosed with fibroids first. Then adenomyosis. They finally agreed to give me a hysterectomy after a six-year battle. While they were in there, they found endometriosis. They told me when I woke up. I was gutted, knowing that the operation wasn't going to cure me.'

'Around the age of 13 is when I started my periods, from the get-go, they were extremely painful. I remember being in so much pain thinking to myself "is this normal?".'

'Heavy and painful periods always (starting age 11, impacting my ability to go to school age 12-13).'

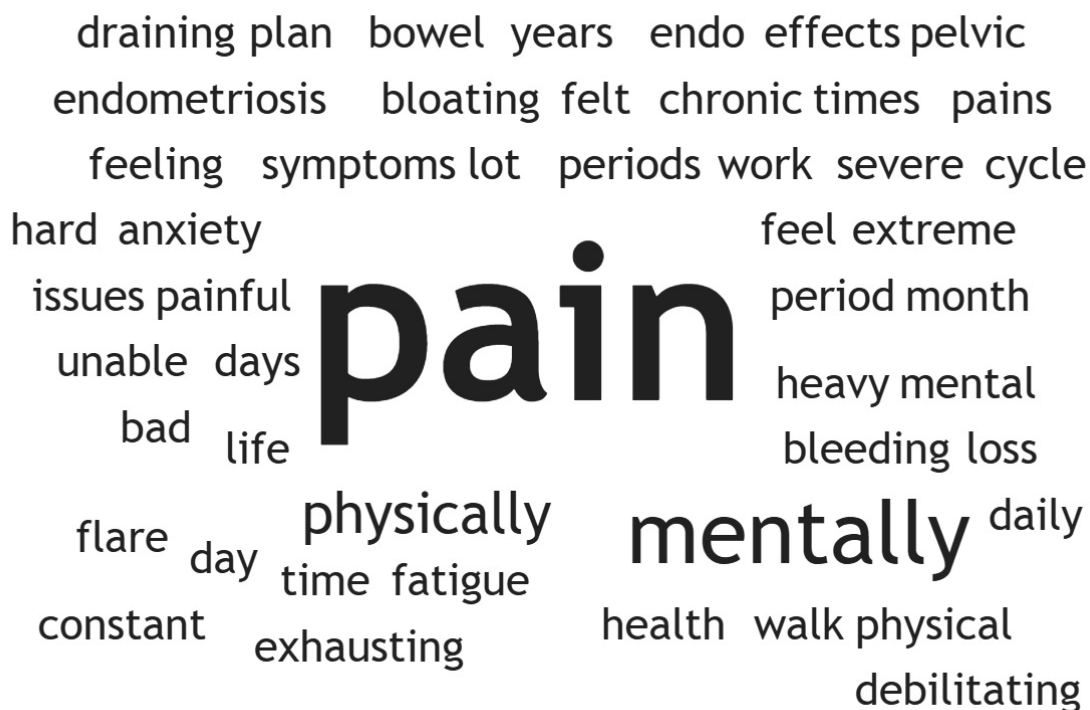
'Twelve years old on my first period – 2012. It was the most painful and debilitating few days that just seemed to get worse with age.'

'I first went to the doctors when I was around 13, I had horrific periods, heavy bleeding and severe pain.'

'I first started experiencing symptoms of endometriosis soon after my first son was born in 2012.'

How do your symptoms affect you? Mentally and physically?

The below graphic is a representation of the words used in the responses given to this question, the largest one being the most used word. This shows that pain is the symptom that most of the women suffered with. The impact of chronic long-term pain cannot be underestimated; women need effective pain management alongside mental health support and understanding from all aspects of society.



'It makes routine daily tasks challenging. It affects the physical/emotional side of my marriage. Work relationships can be difficult due to regular absence. It is mentally draining to cope with the constant pain/discomfort, cycle of ongoing treatment without the hope of a cure.'

'Constant pain, often bed bound having to miss lectures and social events. Mentally draining, scared of what my future looks like.'

'Physically - I suffer with horrendous pain during my period, the pain causes me to pass out, vomit and have issues day to day- such as with food, being able to sleep and work. Mentally it has been a horrible journey. I have suffered with social and health anxiety due to my condition, fear of not being believed by medical staff and by people in my life, worry about fertility etc. Then the symptoms present me with a lot of anxiety before my period starts of 'how bad it will be'. I often experience imposter syndrome- after years of being made to feel that endo is 'just period pain', so I often feel like a burden or an exaggerator.'

'Endometriosis has ruined my life. I struggle now with severe pelvic pain that radiates down by my legs, some days I'm completely unable to walk. I've lost friends because they're unable to understand why I'm having to cancel plans. I am in pain all day every day. I have had two surgeries so far and have a third scheduled for next month. I'm 22.'

'Extreme fatigue, painful intercourse, really low mood, not feeling in control of my body.'

'Very heavy bleeding. Bleeding through clothes. Makes me very anxious when going out.'

'I have pain daily, which sometimes leaves me bedbound, excruciating pelvic pain, bloating, nausea and constipation are my main physical symptoms. Mentally when I'm in a flare up, I am so depressed, I am fatigued all the time and I feel hopeless.'

'Fatigue, nausea, extreme pain, fainting, bloating, abdominal pain, chest pain, back pain, issues walking, low libido, dizziness, loss of appetite, vomiting. Anxiety leaving the house in case I experience a flare up, loss of jobs and issues with attendance, imposter syndrome thinking it's 'not that bad' or I'm 'overreacting'.'

'They make me extremely tired and sometimes anxious. The stabbing pains stop me from being able to go out and enjoy life. It affects my bladder - at night I feel like I need to pee when I don't which stops me from sleeping. It affects my bowels - painful bowel movements and bloating - making me worried about going in public.'

'I felt like it was in my head, like I had to get on with it because it was a period. It was isolating having no one believe you and think you were dramatic because you're in pain. I couldn't do PE and felt PE teachers hated me, I would flood through clothes at school. I now have crippling back pain and am bedridden certain times of the month. The mental effect of not being believed runs deep and I don't trust many health care professionals.'

'I felt like it was in my head, like I had to get on with it because it was a period. It was isolating having no one believe you and think you were dramatic because you're in pain. The mental effect of not being believed runs deep and I don't trust many health care professionals.'

'The pain itself is the most debilitating symptom. It is constant, unrelenting, and resistant to painkillers. At its worst, it feels like my abdomen is being ripped apart, set on fire, and constricted all at once, while my bladder and bowels throb with stabbing pain. During these episodes, I experience nausea, sickness, and cannot stand or walk without assistance. I often need help with basic tasks such as dressing.'

'Mentally, it's very draining, my symptoms have caused a lot of depression, anxiety and stress! My symptoms cause me to feel vulnerable and isolated.'

'Daily pain across my whole body. Not knowing what I'll wake up to. Mentally struggling with not knowing if it'll ever go away.'

'I'm now on the IUD, so I have no symptoms... BUT this has been crippling mentally and physically my whole teenage and adult life. I've also not been able to have children.'

'Over the years there has been times where I have felt afraid to leave my house. I was diagnosed with stage 4 endometriosis, suffered discharge, undergone six surgeries including a bowel resection and full hysterectomy. Physical there were weeks at a time where I couldn't even walk due to pain. I felt alone, I was lucky to have a very supportive partner, who has been there for every step, every appointment.'

'It's meant I couldn't go to school, then impacted my degree. It's made me change careers. This means financially I struggled. I find it very hard to deal with and have weekly therapy. I've had three operations so far. I am now infertile.'

'I am in pain on a daily basis. It's affecting every aspect of my life, and my endometriosis has got so severe that it's stopped all my social and sporting activities and I've had to find a remote job. I've become isolated and my mental health has been severely affected, and I now need major surgery.'

'Severe pain for at least five days out of 25 days. Sometimes pain around ovulation too. Unable to travel or move around during these times, can't be away from a toilet.'

'They are there every day. I feel alone and at times depressed. My dress style has changed as I can't wear tight clothes anymore. I always have to have a toilet nearby as I also have IBS. I don't really go out.'

'They affect every part of me. I am mentally and physically exhausted. I work full-time, and I struggle to perform at my best and have a normal social life. I always thought it was in my head as I kept being told it was just a bad period. Just take contraception or have the coil.'

'The symptoms have impacted on all aspects of my life socially, professionally as well as mentally and physically. Bleeding outside of my period, pain before during and after, the chronic fatigue it all has a physical and mental impact. The constant dread of, not knowing whether today will be a good day or a bad day. Having to function even on days where you are finding it difficult to stand up straight or get out of bed. The cyclical nature of the condition is horrific, its constant it's not going away, there is no cure. Physically and mentally exhausting.'

'Mentally... Hugely! All the hormones I've been prescribed to try tackle the symptoms have beaten me down mentally. I've lost jobs, been suicidal. The severity of my periods is on another level, I'm off work every month so yes, it impacts every aspect of trying to live a normal life. I can't plan my wedding, holidays etc in case I'm "on" or unwell on the day. I've also got a

severe back condition due to fainting onto my coccyx at the age of 14. Have degenerate disc disease in lower back and complete muscle loss. Every month my symptoms are fainting, vomiting, poor bowel control, very low blood pressure, acid reflux just to name a few. It's fun!

'I have been very suicidal at times and have not wanted to wake up to just experience another day of unbearable pain. Physically, I had to give up football which I loved, I can't walk very far and often need help with stairs and getting by in and out of the bath.'

Have you felt listened to by health professionals?

Thirteen women stated that yes, they had felt listened to by health professionals. 108 women stated no, they felt that they had not been listened to by health professionals. Many felt they had been 'gaslit' when trying to explain their symptoms. It has taken years for many of the women to get a formal diagnosis with many being diagnosed with other conditions first including IBS and PCOS.

'No not always, I always felt as though I was being brushed off and made to feel like it was all in my head or normalising my symptoms.'

'NO! As a teen was put on the pill. Early 20s taken off it with next to no support and put on anti-depressants. Late 20s told to "have a baby" and discharged. Late 30s told to have the coil which became lodged and tangled in prolapsed fibroids. Bled for a year straight until they could get it out. Now early 40s back in limbo waiting...'

'No. I was told recently by a Gynaecology consultant, following my hospital admission due to anaemia, that I have no symptoms of endometriosis. To be clear, I have ALL the symptoms of anaemia listed on the NHS website. She specifically told me that heavy bleeding was not a symptom of endometriosis. My mum, aunt, and nan all have endometriosis as well. I'm 26 and so worried that it will affect my fertility but have been given no options by professionals.'

'No. Seen multiple professionals and got told to try the pill or have a baby as it's "normal". Lots of gaslighting and had to go private to get checked out.'

'I have felt listened, but I have had to push for answers. From the first time I went to the GP about this, it took me nine years to get a diagnosis. The process can be exhausting as you feel like a hypochondriac and like it is in your head, when it isn't. Unless you advocate for yourself, it's easy to not get a diagnosis.'

'It took four visits to the doctors; on my last visit I hadn't even gone to talk about my symptoms - I was just having a medication review. While I was in there, I asked the nurse if two of my symptoms on my period were normal as I had been told for 11 years that they were and I thought different. The nurse was horrified I hadn't been listened to and booked me an appointment with the women's health specialist straight away. So no, up until the last visit I didn't feel listened to.'

'Only on occasion. I finally found a consultant who listens to me and my concerns, but he is so busy that he can no longer take time to listen to everything now. GPs are unsympathetic and if I have any issues, they merely tell me to speak to gynaecology - well, getting an appointment with them is like finding gold.'

'Not at all. I was told that I was overdramatic, attention seeking or that it was all due to stress. I even watched a GP Google the condition after he refused to accept it was a real medical issue.'

'I was very fortunate to have an understanding male doctor who referred me when I was 23 and he actually started in his referral he suspected endometriosis. His suspicion was proven right by gynaecologists. 30 years on I do not feel I am being listened to now.'

'Luckily, I had a cancer scare which sounds silly but because of that I had a lot of tests in a short amount of time and when they suspected endometriosis, I was then referred to the endometriosis team.'

'Not all of them. My current GP is fantastic, has worked with me the best she can to manage the pain. However, I had to fight for over 8 years to actually have a scan or laparoscopic surgery, which is too long.'

'My relationship with healthcare professionals is complex. I've had to learn to advocate for myself. I'm fortunate that I work in healthcare (non-clinical) and am educated and confident. I feel I can force professionals to listen to me and take me seriously; however, there's so many others who can't. The average diagnosis is 7 years, that's not normal or acceptable. I was fortunate that my official diagnosis came after 3 years. The consultant that belittled me before my first surgery is a prime example of dismissing women's health. Putting it down to anxiety, depression, painful periods being normal.'

'No. I was told the pain was in my head or that it was "probably an STI" despite never being tested positive for any STIs. One time a doctor berated me and said "Do you think you have cancer or something? Why do you keep coming in about this pain". Yet despite telling me it was in my head they put me on anti-depressants, codeine and Naproxen. These later damaged my stomach lining.'

'In 2024, I was referred to an Endometriosis Specialist, who, to date, is the only medical professional I've spoken to who has an excellent and thorough level of knowledge of the disease and how it affects people, but this took years to receive, and, following my laparoscopic surgery and diagnosis, I was discharged from the service without so much as a heads-up about where I could go or who I could contact if I have any problems or changes in my symptoms. Apparently, Colchester General Hospital is supposed to have an Endometriosis Nurse Specialist - but I've yet to hear anything from them, and I think it's possible I've slipped through the cracks and will have to go through the referral process all over again, just to be assigned someone to help me manage my symptoms and pain.'

'The gynaecologist mentioned endometriosis but said it was unlikely but booked me in for surgery to have a look anyway. The day of the surgery, the consultant came in and said, "Endo is just a fancy trend at the

moment; you're probably just thinking you have it because you've seen it online". I woke up with endo discovered and taken off in multiple places, and since then have had a much better life.'

'No, I have been gaslit recently and told that I must have misheard (even though my surgeon told me I had endometriosis and my operative report says the same).'

'Not at all. Dismissed by one female gynaecologist who told me there was nothing wrong, despite scans showing otherwise. Then one year later another male gynaecologist told me, "My god, you don't have a life" and carried out minor surgery. Despite my requests at age 35 I was still refused a full hysterectomy and had to endure another 15 years of hell. The nurse stood by my bed after the (minor) surgery and grimaced that they'd done what they could, but she'd never seen such a severe case.'

'I finally found a health professional who conducted keyhole investigations (at the age of 38). Before then, I was advised I had irritable bowel and I was depressed.'

'Absolutely not, every woman in my family has symptoms or diagnosis and yet I've been told that I'm too fat to be investigated further. I've been gaslit, told that things consultants said at my appointments weren't true and just forgotten about.'

'No. There are a few nurses or assistants who I believe have listened, but they're never in charge of my care, and are overruled by whatever the doctors or surgeons have to say. 9/10 I have a male doctor, who tries to tell me what I'm feeling, when they have NO idea the half of it.'

'It took 15 years to be diagnosed. I have even been told multiple times I was imagining it.'

'Absolutely not! Was told as a child that all woman experience this, it's just your period. Been told to "just put up with it"'

'Absolutely not. I was only taken seriously after a PAL'S complaint. Prior to this a consultant told me, "Your periods can't be THAT bad".'

'In recent times yes, however I was told for a long time that it was bad periods. I was told I had pelvic floor dysfunction and IBS. (Which are still relevant but not the main cause). I was told it was normal; I was told to just breathe through it. I felt pushed aside because I was young.'

'Until I paid privately (ha-ha) ...no. The NHS Gynaecologist actually told me he doesn't think anything is wrong and I just need to learn that some people's periods are a bit 'sore'. - I was so mentally drained I didn't report it to PALS I wish I did.'

'Doctors need to be educated on the woman's anatomy and its health conditions! I've come across doctors that only know the basics about women's everyday lives (health related) yet act like it some treasured knowledge that only the top geniuses know - (and they need to be made aware that us women don't need to be told how it is to be a woman because we're already living it).'

How long have you had to wait for a diagnosis? If you have one or are still waiting to be seen by a specialist.

The women who responded have been waiting for months/years to be seen by a specialist. This has usually followed numerous visits to the GP for their symptoms and at times various referrals to other specialist services to try and diagnose the problem. Women talked about the lack of follow up care, many having been discharged following surgery with little to no explanation regarding what to do if their symptoms returned. This often meant returning to the GP and asking for a referral back to gynaecology which resulted in long waiting times again to be seen.

A new report has shown how long waiting times have become: 'New data released by Endometriosis UK has revealed that the average time to receive a diagnosis of endometriosis in the UK has now reached nine years and four months. Alarming, this figure has increased from an average of eight years reported in 2020.' Read more here: [Endometriosis UK release new report highlighting alarming increase in endometriosis diagnosis times | Endometriosis UK](#)

'I am still waiting on the NHS waiting list after my referral in April 2025. The NHS app said (and still currently says) 22 weeks wait however after 25 weeks, I called the hospital and was told the wait is more likely over 54 weeks. The member of staff who was managing the appointments estimated that my referral from April 2025 would likely mean I should receive an appointment letter in May 2026 with an appointment for June 2026. Given my symptoms, I have personally made the decision to pay for a gynaecology appointment privately. This is not a decision I made lightly as it's costly, but I felt I had no choice and am currently in a position where I can afford it, I know many others aren't as fortunate. So far, I have had an initial appointment, where the consultant made me feel listened to for the first time, took my symptoms seriously and confirmed my symptoms did not match my previous diagnosed PCOS condition. I am currently having further scans and blood tests of which I have paid for privately and have been told I will likely need keyhole surgery to confirm.'

'Nineteen years it took to get a diagnosis, and I had to pay privately in the end because my mental and physical health was so poor.'

'I was told in my teens I have endo. In my 20s told I have endo. But told again in my 30s no actual definite diagnosis. Also told I have adenomyosis. And fibroids. Oh, and a polyp. Literally don't trust they know what they are talking about half the time and just want to give up.'

'I started symptoms in my 20s and was diagnosed late 2023 via MRI. I was 50'.

'Waiting to be seen again as in the process of diagnosis I got pregnant and had a baby. The symptoms in fact did not improve. I'm 30 now, I first saw a professional about debilitating symptoms at age 12.'

'I waited two years from age 17-19, BUT I was only diagnosed because I had a cyst 10cm and it had to be surgically removed, and in that surgery, they saw the endometriosis. Before that surgery, I had never heard of endometriosis.'

'Seventeen years and only by chance because I had a blockage in between my kidney and bladder.'

'I was likely to have figured it out for myself due to family history and therefore asked the right questions and was diagnosed within three years.'

'Six years I've been asking for help at my doctors. It took a new female doctor to start before I was listened to.'

'I had a diagnosis within six months of referral.'

'Finally diagnosed with adenomyosis this year. Awaiting second opinion for endometriosis. So, five years and still fighting.'

'I started my journey of seeking help at 12 years old, I was 26 when I was diagnosed.'

'Six years. My doctor got fed up of me moaning I researched and asked for a referral, and he eventually gave in now under the endo clinic at UCLH which is amazing!'

'I have waited 15 years. I have had children in between and this had an impact on the care I received, because I was often told to wait a few years after I had my children for my hormones to settle before coming back.'

'Nine years. Got diagnosed in May 2025 over the phone. So severe my local hospital won't treat me and waiting to be seen by a specialist. At least 16 months wait to see a specialist.'

'From about the age of 14 (1988) until 31 (2003).'

'I have been going to the doctors, hospital and emergency treatment centre since 14 with symptoms. I was diagnosed in 2023 at the age of 23 but with no clear path forward. I have been left with the statement 'if you want to have children then surgery is not recommended yet, we will check in with you in ten years and see what you would like to do at that time'

'Five years for a formal diagnosis. Many scans and lapa in that time. Then a lapa was carried out by Dr * and he found stage 4 endo - plus other stuff I was diagnosed with. How can this have been constantly missed? I only get

to see Dr * once a year because the waiting list is so long / too many patients. This means treatment is often delayed / my journey stagnated because of the delay in seeing him. Waiting list for my hysterectomy has been a year and a half.'

'My symptoms started at 14 and my diagnosis was at 29 so fifteen years it had taken for a diagnosis.'

'I was first seen in 2007 and was diagnosed in 2010. I feel lucky compared to some. However, after my second child I was still having so many issues. It was also suspected that I had Adenomyosis, to which I requested a hysterectomy. I know it isn't a cure for the endo, but I couldn't live life how I was anymore. My relationship was on the rocks as I had zero interest in sex as it brought nothing but pain and flare ups for days after, I was pretty much continuously bleeding for weeks on end. This process took nine years!'

'I suffered for around three years - seeing the doctors regularly and being told I had sensitive ovaries, heavy period pains, then pelvic inflammatory disease. I approached the doctors when a friend gave me a clipping about endometriosis - took the clipping to the doctors and said this is what I have and I need a laparoscopy!'

'I don't have a formal diagnosis, just a note on discharge papers from a sterilisation operation and a doctor that 'thinks' I probably have it.'

'Five years and that was only when I had the resources/family financial support to pay for a private MRI.'

'I was diagnosed at the age of 50 in 2022 after I had requested an MRI. I had been a patient at the same gynae department of my local hospital for twelve years before diagnosis. I am now under the endometriosis department of the same hospital and awaiting a hysterectomy due to the additional problem of adenomyosis.'

'I waited three and a half years to get my diagnosis, then a further year and a half for my surgery, only for it to have all grown back a year later, and I'm now on more wait lists for help - with no clear wait times.'

'I was diagnosed at 42! I first had symptoms when I was 13/14 and now waiting times to see a gynae have been over a year. I've been referred back as my symptoms worsened (likely due to perimenopause) and been waiting 15 months and still not got a date for an appointment.'

'Haven't been diagnosed.'

'I have had an MRI which I waited from September to end of December to have. This showed endometriosis and adenomyosis which I am now being referred to either gynaecology in Broomfield or the endo specialist centre in Colchester (my GP is struggling to get a hold of them).'

'Technically around four years since I actively started pushing for a diagnosis, which isn't long compared to so many other women, but those three years were absolute mental torture for me and those close to me. In reality, a doctor should have picked up that something was wrong with me since I was a young teen and done some tests then, as I displayed warning signs of Endo really early on. So that would make it fourteen years.'

'I waited approximately 8-9 years from when I first went to the GP to when I first got diagnosed officially with Endometriosis.'

'I was refused a referral three times by my old GP. So, I went private to see a specialist. I got my diagnosis in August 25. Or sadly I would have still been waiting. I tried from Dec 24 to June 25 to get my doctors to send me to a specialist.'

What support do you have? Friends, family, employer, online or face to face support groups etc.

Most of the women stated that they had support from family and friends. Many were members of online support groups, but some found these unhelpful as they could be very negative and didn't provide much practical or emotional support. Some mentioned that the thought of attending a face-to-face group could be very overwhelming which was a barrier for them. Many stated their work was supportive which is very

encouraging, but others had lost or had to leave their jobs due to levels of time off because of the endometriosis.

'I do bank shifts - luckily the manager knows my condition and has said if I need to go home at any point to let her know. I don't do face to face support groups as none are local to me. (I'm from Suffolk but see a specialist in Essex and my partner is also from Essex) - I have a few friends I contact and there is the Endo UK page plus their chat team.'

'My partner has been very supportive and tries to learn about best to support my symptoms. I haven't shared it with family. My line manager is aware at work, but I currently work mainly from home so have been able to manage symptoms whilst still working.'

'Amazing friends and family support. Employer understands but am still under HR review due to company policy.'

'Employer is supportive, and I am able to work remotely when needed. Never attended support groups as I'm not comfortable. Close family are understanding but they all live abroad.'

'Employer was awful so I left and retrained so I could work for myself. Friends up till recently were not too supportive and I'm sure thought I was making it up or attention seeking. Family have been good but now so used to me having treatment it's not a big deal.'

'I have a best friend who also has endo so I feel support from her, but she has a family to worry about. I get very little support from family and don't want to burden the few other friends I have. My manager at work is supportive in allowing me to attend appointments but I do feel pressure not to have any sick days'.

'My family are very supportive as is my employer however my sickness record is worrying me as I keep having to take time off. I'm a member of online support groups but I sometimes feel that these are just forums for people to voice their opinions about wait times etc and that isn't always helpful.'

'I work as a teacher, and my workplace do their best. The bottom line is that endometriosis can cost you a career.'

'I have my husband, parents and friends, but it's very misunderstood and online support groups have been the best thing to help. Past employers haven't been very supportive; it doesn't seem to be treated as seriously as other disabilities.'

'My partner. Our families. My friends, both in person and online. The many wonderful individuals I've interacted with through various endometriosis support groups.'

'My family and a local endometriosis support group set up by the NHS PCN'.

'My family especially my husband has been absolutely amazing, it's not just me this affects or changes my life, it's his too. I've lost friends whom I was closer with before all this, due to me having to cancel plans and not drinking as had to change my whole life. I've got friends who also have endo and I've got friends who don't but don't judge me for cancelling or having to change my whole age, my lifestyle, they take me how I am good and bad days, just means my circle is much smaller than it used to be. I have some endo support groups online which have been helpful. I work and my employer is great due to having to take off for multiple hospital appointments.'

'Online support group (I find the in person one in Colchester quite depressing and the seats are uncomfortable). Friends have been understanding but drifted away. Family similar. Good partner and employer'.

'Support is variable. Like anything some people are more understanding than others. I am fortunate to have an understanding employer who will make reasonable adjustments within the workplace if required. I have a great support network of family and friends. I attend the recently established support group in Rayleigh and have followed Endometriosis UK and other groups on social media. I am now under the care of UCLH, and this has been a game changer for me.'

'Family. Nothing else and even that was only after surgery as nobody believed I could be in so much pain just because of periods.'

'Friends and family have been somewhat understanding but as there isn't much research it's hard for them to understand fully what I have been going through. The TikTok community has been my biggest support and place for information.'

'I have friends who have formal diagnosis and others who are experiencing symptoms and pursuing diagnosis, but it seems to be more of a shared trauma rather than support. There is nothing anyone can say or do apart from suffer together and it is heartbreaking. Work are not understanding in the slightest even though I informed them of my struggles when joining, I'm still blamed when the symptoms get too much.'

'In the beginning, I had no support and was a single parent, so it was very difficult to cope. I had extreme depression from the pain and anxiety when leaving the house because I was scared the pain would start while I was walking down the street.'

'Very little. Single person. Few family members. Teacher so unable to work from home. A couple of good friends who help when they can.'

'I have unfortunately had to quit my job; lost the support of colleagues and management I've lost friends and have no family in my life. I have a 3-year-old son who's my whole world. I'm in a few Facebook groups for those with endometriosis which is supportive in knowing that I'm not alone.'

What can be done by the NHS/health professionals/employers etc. to help support and understand women with endometriosis?

'Listen' was the word used the most by women who responded to this question. So many of them have felt unheard/ignored by health professionals when trying to talk about their symptoms. There are signs that some employers are becoming aware of endometriosis and how it can impact the ability to work and women have talked about reasonable adjustments being made which is very positive but many still have to go

through sickness/capability procedures due to their levels of sickness which causes stress and worry. Education and training, not just for GPs but for all health professionals who may have contact with a woman experiencing endometriosis. And early education for young people, not just young women but all young people so they aware of the symptoms and have the ability to ask for help sooner if something is outside of the 'normal' when having periods. So many of the women in this project said that they didn't know that what they were going through was not normal as they didn't know any different. They often thought that all women experienced the pain that they did.

'LISTEN! Stop ignoring the wisdom a woman has about her own body and trust the patient's judgment. I know my body better than any doctor, and yet no one ever listened to me, and that lack of listening could have cost me my bowel. Women need to be treated as a whole for endometriosis. It's not just a period problem; this is a whole-body disease. Women need nutritional help, mental help, physical help, and to be treated as a whole.'

'Overall - there just has to be more awareness on what endo is and how it differs from a normal period. People need to know that it cannot be compared to a normal period. You cannot function to the same level with Endo that you would when on your period! And that it's not even really period related. So many times, I've heard people say it's to do with your period. And even though Endo can develop a monthly cycle for SOME women, it overall is an isolated system and should just be removed from having anything to do with a woman's period at all.'

'We need more education around endometriosis for health professionals, currently I am having to lead discussions when I go to appointments about it (e.g. did not know about NICE guidelines around endo being on bowel means seeing an endo specialist). There also needs to be more specialist centres in Essex, the waiting time is so unbelievably long for such a serious issue. Employers should be where possible allowing people with endo to take time off or work from home when symptoms are most serious.'

'As this is a long-term condition, reasonable adjustments should be agreed between the individual and line manager in order for them to be well supported in the workplace. This may include: • Working from home, if possible • Ensuring that any absence is correctly recorded so as not to trigger the standard sickness absence occurrences. • Being supportive if the individual requires surgery and ensuring that a suitable phased return is arranged. • With the individual's consent, educate the team on the condition so that they too can be supportive. Understanding how anxious sufferers feel during their period in case they leak, what happens when a flare up occurs and the crippling effects this can cause. This will alleviate a lot of the anxiety that endometriosis sufferers experience as they don't want to be a burden or let colleagues down, therefore ensuring they feel supported is vital to their staff experience.'

'More awareness into endometriosis, being more empathetic towards individuals, exploration into symptoms earlier and not pushing contraception to being the cure.'

'GPs need more education on endometriosis. From my experiences it's clear there is a limited understanding of most gynaecological issues which led to a late referral. It's really important to make the patient feel listened to and I don't think I experienced this with either GP I saw. The waiting list. I understand the pressures on the NHS but telling patients the waiting list is 22 weeks when its more than double is not fair. It gets patients hopes up that they'll soon get answers to their pain when it's not a true reflection of the wait.'

'Better access to specialist women's health practitioners. Stop downplaying our symptoms and start believing us when we tell you there is something wrong.'

'Start taking preventative action rather than a reactive response. The ibuprofen equivalent prescribed to me for period pain won't save my fertility. Why is it so hard to get a laparoscopy for diagnosis? This isn't even a wait list problem for me; I was just told no. Consultants especially do not listen and make presumptions about you before appointments. My

experiences in 2024 and 2025 have left me completely unable to trust the physical health care provided in Essex, and it all comes down to the same thing: clinicians do not listen to you.'

'They should stop dismissing women's symptoms and worries and telling them everything is to be expected because we are female. I simple MRI scan detected my endo and adenomyosis. More simple tests should be available. Gynaecologists and GPs need to listen, we know our bodies.'

'Listen and get to the right people to discuss all the symptoms and how to manage them both surgically and holistically. Physio, mental health etc. It needs a multi-disciplinary team that understands endo and its effect on the whole body including the nervous system.'

'Early diagnoses, not being discharged when it's obvious more treatment will be needed in the future. Perhaps writing a letter to be shown to employers outlining the way endometriosis affects women.'

'I think keeping people informed. I've had so many appointments cancelled/changed, it's so frustrating. I currently have a provisional date for surgery but appointments with my consultant keep getting cancelled so I have no idea what is going on.'

'It needs to be seen as a whole-body disease that affects women every day instead of just a period disease. There should be emphasis on the fact that there is no cure, and we have to manage it with their support - working from home should be recommended when needed, it shouldn't have to be planned or only during a period. Heavy bleeding is just part of it; it should be emphasised how it affects pain and energy levels so people can empathise and understand more.'

'Listening to women. If we tell you that our periods are really heavy, painful, experience pain during/after sex, we get pains in our legs, pain when urinating/having a bowel movement don't dismiss them especially if they are linked with our periods. We haven't come to the doctors for the fun of it, we've come to have someone help us. Do not normalise heavy painful periods too. We know our bodies.'

'The more people who speak about the condition and advocate for women living with endometriosis the more it will be taken seriously. Society belittles women's healthcare often. Medical research is a million miles behind for women, if men were living with this problem, there would be a cure already. An open dialogue needs to be created so women feel comfortable taking a day off sick for period pains or listened to by GPs.'

'Quicker diagnosis. Raising awareness with wider communities and employers.'

'For earlier referrals, GPs to listen and not just prescribe the pill.'

'There should be education in schools for young girls about symptoms to look for... early diagnosis can stop progression. Specialist smear test appointments for women with endo/trauma (I have never had a successful smear test due to my inability to have one because of the pain caused when nurses have tried and not enough time or training of the nurse in the appointment to complete).'

'More communication during long waits for appointments and procedures. I have been waiting for an appointment with UCHL for 17 months!'

'Education incorporated into the curriculum for young women and girls to enable them to recognise the signs and symptoms. This should include some sort of education for men and boys as they have mothers, sisters and may go on to be someone's partner. Employers to recognise the disabling nature of the condition and the impact it can have on day-to-day function so that they can make reasonable adjustments within the workplace. Health professionals to have access to CPD to ensure that they are well informed and are as up to date as possible. Annual health checks with specialist nurse for women diagnosed with the condition to ensure that the treatment they are receiving continues to be appropriate. Reduce waiting times for referrals. Consistent access to advice and clear treatment options. At the moment women's experiences vary depending on where they live, who they see, from trust to trust or hospital to hospital.'

'JUST LISTEN!!! Every woman is saying the same thing but there is postcode lottery on health. We want to work but need realistic support as the added

stress of lack of support worsens the condition. Not one solution solves everything, it includes diet, exercise and mental health is needed combined to support people. This doesn't just impact each individual but their household members too.'

'An update in training, some GPs became professionals years ago and still have a very old view. More research needs to be done into women's reproductive health and endometriosis.'

'Diagnosis has to be holistic. It isn't just gynae it impacts the whole body, and I feel that if endo was treated more holistically at a GP level, it could more easily be fast tracked for diagnosis. It shouldn't be the last condition they investigate when so many women have it, and the symptoms are quite consistent. I think the biggest improvement actually needs to be in schools as that was where I had the worst experience with Endo (PE teachers have put me off sport for life!).'

'I ask them to always investigate even if the patient is young. It always frustrated me that doctors would say I looked well as I have always worn make up and made an effort with my appearance. Even now others are in disbelief that I suffered from this problem as it is invisible to most. It is extremely painful.'

'Better screening and to actually listen to women when they say things are not right. We know our own bodies. We are also fed up being told are pain, heavy bleeding, painful ovulation etc is just the kind of things women have to put up with.'

'More research! Taking women seriously when we come with these problems and not just pushing us to go on contraception. All the help offered is short term. Shorter waiting time for appointments and surgery.'

'Train more doctors etc in women's health. I know it's a complex sector, but we need as many people helping as we can. Train them in support and how to talk to a patient with care and understanding, not just medical terminology and a cold face. Offer updates on wait times and don't dismiss patients when they're telling you they're in pain. Push more money into trying to find a better treatment or even a cure. Half the doctors I've seen

didn't have as much knowledge on this condition as I've found through my own research.'

'There needs to be far more research into how endometriosis truly manifests and affects the body. Current understanding is limited, and treatment approaches need urgent review. Endometriosis is not just a reproductive condition—it behaves more like a systemic disease, often compared to a benign cancer because it can spread throughout the body and attach to any organ. Even when oestrogen production stops, Endometriosis can create its own supply, meaning menopause does not cure it. Key improvements should include: validation and belief. Women need to be believed when symptoms return after treatment, rather than being told "it can't be back." Reduced treatment times: waiting years for surgery or specialist care worsens the disease, leading to more complex surgeries and complications involving other organs like the bowel or lungs. Continuous care: once diagnosed, patients should not be discharged. Like cancer patients, they should receive regular follow-ups and ongoing management. Education for GPs: GPs are often the biggest barrier. They rely heavily on blood tests and imaging, which do not definitively diagnose endometriosis, and dismiss symptoms instead of acting on them. Better treatment options: hormone therapy does not always work and often brings severe side effects that make life even harder. Public awareness and education: endometriosis is still not widely spoken about. Many young girls start their periods with severe symptoms and are told this is "normal." Education could prevent years of suffering. Employer support: employers need awareness of the impact endometriosis has on daily functioning and provide flexibility and understanding for those affected. Currently, there is no definitive cure, and Endometriosis will continue to regrow. With 1 in 10 women affected and waiting lists for surgery so long they could fill Wembley Stadium three times over, urgent action is needed to improve research, education, and care pathways.'

'More research. Validation. Work on waiting times. Better pain relief without being made feel like I'm a drug addict.'

'There needs to be more empathy. There needs to be more knowledge, that diagnosis/treatment/planning is not just down to one person - the whole team at the gynae outpatients and also on the hospital ward, need to be better qualified. My real concern is if there is only a select few, what happens when those select few leave the hospital? My care has only been taken seriously/adequately when I have put complaints into the PALS team, until then I am ignored / dismissed. I am fortunate, I am a professional, strong, white woman - who can advocate for myself quite well - if I wasn't, I fear I would have waited longer and how many other women are in my situation but aren't taken seriously because they aren't as fortunate as me?'

Demographics

Optional questions completed by the survey respondents. Response total may differ from total respondents (136) as these questions were not compulsory.

Please tell us your age			
Answer Choice		Response Percent	Response Total
1	18 - 24 years	4.4%	6
2	25 - 49 years	80.7%	109
3	50 - 64 years	14.1%	19
4	65 to 79 years	0.7%	1

Is your gender identity the same as your sex recorded at birth?			
Answer Choice		Response Percent	Response Total
1	Yes	100.0%	135
2	No	0.0%	0
3	Prefer not to say	0.0%	0

Please tell us which sexual orientation you identify with

Answer Choice		Response Percent	Response Total
1	Asexual	1.5%	2
2	Bisexual	7.4%	10
3	Heterosexual/straight	87.4%	118
4	Lesbian/Gay woman	1.5%	2
5	Pansexual	0.7%	1
6	Prefer not to say	1.5%	2

Please select your ethnicity

Answer Choice		Response Percent	Response Total
1	Asian/Asian British: Indian	0.7%	1
2	Black/Black British: African	0.7%	1
3	Mixed/multiple ethnic groups: Asian and White	0.7%	1
4	White: British/English/Northern Irish/Scottish/Welsh	90.4%	122
5	White: Irish	1.5%	2
6	White: Gypsy, Traveller or Irish Traveller	0.7%	1
7	White: Any other White background	4.4%	6
8	Prefer not to say	0.7%	1

Postcode area

115 women gave the first part of their postcode:

65 women were from mid/south Essex.

45 women were from north Essex.

5 women were from west Essex.

2.3 Interviews

Over 90 women offered to talk to us on a one-to-one basis to share their experiences. We were unable to talk to everyone due to the timescale for this project, but all the women were contacted and given the option to share more details regarding their experiences in writing.

Below are the one-to-one interviews that we did complete. Thank you to all the women who took part and spoke so openly about their situation.

Ava*

Ava is a CEO of a charity based in Essex and lives with her partner.

'I started getting symptoms just after my periods started at the age of 11. I did not know that I had endometriosis until I started fertility treatment, because nobody had thought to tell me.

After a couple of years of getting more poorly every month, really heavy periods and loads of pain, I went to the doctors, they put me on iron tablets, but it wasn't getting better so they put me on the contraceptive pill, spoke over my head to my mum and I just accepted it. I carried on taking the pill until I was about 20, by this time I had been on the same pill for 7 years. I went back to the GP to see about changing it, I tried some others and then I decided to come off it, but the pain came back. I saw the GP and was told that if I wanted to start a family, no one would listen until I had been off the pill for 2 years. So, I did that and kind of toughed it out. I wanted to start planning for a family, but nothing was happening, I kept going back to my GP but it was a difficult experience as she had three maternity breaks during that time and told me that as soon as I stopped worrying about it, it will happen, but it just wasn't happening.

By the time I was nearly 30 I was getting really frustrated and broke down when I saw a locum GP, he said sorry and referred me straight away. At my first appointment with the consultant, she told me that having endometriosis and polycystic ovaries was going to be problem when trying

to get pregnant... this was totally new information to me! I had no idea, so I went and did some research and suddenly everything made sense, the pain, I had tried various exercises, chiropractor etc for lower back pain but it was the endometriosis and I never knew.

After trying fertility treatment and none of it working, I made the decision to have surgery, this meant not being able to have a family, but it did enable me to have my life back. I lost weight, was able to have the energy to maintain regular exercise etc. I am now entering perimenopause but have spoken to a pharmacist who was really lovely and told me that it may flare up the endometriosis symptoms but it should all stop once I have gone through the menopause. It's not too bad at the moment. I have always found a pharmacist more helpful than a GP.

I have had good and bad experiences with health professionals of both genders. Being female does not mean that you are any more understating. The locum GP who referred me was male.'

How did the endometriosis affect you when you were younger?

'When I started secondary school, I just didn't go when I had my period as I just bled through everything, I felt terrible, drained and tired but also so embarrassed. I couldn't go to the toilet when I needed too, not enough time in between lessons and was hard to get a toilet pass from a teacher. It was all super awkward and super embarrassing. It was a taboo subject, and I didn't have anyone to talk to; I grew up with lots of brothers and wasn't able to talk to my mum about it. Her religion also made it hard to talk to her about what I was experiencing and so by not being able to talk about it, it made me feel like it was a sin, dirty and guilty.

I wish I had known about my endometriosis earlier, maybe I could have something different about it.

People need time, patience and understanding. Multiple miscarriages, polycystic ovary syndrome, endometriosis etc., if a medical professional does not have the time to listen then they can refer to organisations that can. Improved information on what other support is available.'

What needs to be better in the future?

'Both girls and boys need to be educated about endometriosis. People just need to be more aware and have a degree of understanding.

We can't forget the men and boys in this, it's hard to watch someone you love go through this. Knowledge is power, they need to know what helps and what hinders.

The cost of sanitary products is extortionate and there should be free supplies in every public toilet. If you are having a bad flare up, then you can use a lot of products.

It isn't an NHS problem, it's an everybody problem and will only get fixed with an everybody solution. Local authorities, education and the wider media.

In 2026, having a period should not be taboo. It should be a normal thing that we can talk about without shame or stigma. We are getting better but still have such a long way to go.'

Priscilla*

Priscilla is a mum of two children with additional needs and runs her own business. She suffers from Long Covid and EDS-Ehlers-Danlos Syndrome.

'I don't currently have a diagnosis of endometriosis, I have asked my GP to refer me to gynaecology, but she has said that she won't do that until I have tried the pill or the coil. I have tried many different contraceptive pills in the past and they make me feel suicidal. I refuse to put myself through that again when I have a business to run and a family to look after.

Every month I am in agony with pain to the point where I am rolling around on the floor, I have very heavy and long periods, I also feel very dizzy and generally unwell. This has a massive impact on me as my business is sports based so very physical.

I have had an ultrasound, and it showed up a cyst on my ovary but that was it. I felt that I had to jump through hoops to even get that. I have spoken to a private GP via my husbands work health plan and she advised that I see a gynaecologist, but the plan does not cover for them to make a referral, so I feel very stuck, my NHS GP won't make the referral, it's just not fair. I wake up every morning and must carry on; I don't have any other option.'

Enya*

Enya lives with her family in Essex.

'I was having private treatment for Lyme disease, and my periods became really bad. The specialist who I was seeing for the Lymes treatment thought it may be endometriosis; they wrote to my GP asking for them to make a referral. When I saw my GP, she just laughed at me and said, 'Why are you spending money on wacky doctors?' so I ended up paying for a private gynaecology consultation who did refer me for an MRI scan through the NHS.

I have been in so much pain that at one point I pooped myself. I suffer with dizziness, amenia, depression and anxiety.

I have good family support and have found some online support groups helpful but attending an in-person support group can be overwhelming and cause anxiety so I prefer the online option and feel that needs to be an option for more people to access.

I would like to see more information posters in GP waiting rooms about all aspects of women's health.'

Georgina*

Georgina works in a corporate role and lives with her partner.

'This has been a very long ongoing journey, but really probably started back when I was 11.

When I had my first period, and since then, they've been extremely heavy and painful and getting a stabbing pain in my pelvic area and not telling anybody because it was around my period and I thought they mentioned you get cramps, it's probably just that. But I was like, how do other people cope with this? Because I'd have to lie down and felt quite faint sometimes, and I couldn't walk. I didn't say anything to my mum or anyone for about two years. I coped with it internally because I thought everybody must be having the same experience. It was how heavy my periods were. I remember when I was 11 years old going to a friend's, she had a brother and the three of us had gone to the park, we're playing having fun and on the way back her brother saying oh you've cut yourself and I had bled through my leggings and through my top and still to this day I feel the shame and embarrassment. And that's just one time that it's happened. I was in my early 20s and working in an office, I remember getting up from the office chair and seeing a patch of blood, I didn't say anything because I was so embarrassed again. I remember someone making a comment about it and I just didn't want to go back for the next day. So, it's things like that I've been struggled with, it's made me quite an anxious person.

I eventually told my mum, and we went to the doctors, they prescribed me the contraceptive pill, but it didn't make any difference to the pain or the bleeding. I then had various tests and scans, but they were not finding anything. After a few more years of suffering with the pain, I saw a gynaecologist and she suggested a laparoscopy, when I came round from the surgery the doctor told me they found some mild endometriosis, my bowel was stuck to my stomach wall and that they had got rid of what they could. And then that was it, the doctor left. I had just woken up from a very traumatic experience to be given that information and there was no follow up. Six months later my symptoms came back. By this time, I was able to access private treatment through work, I had another laparoscopy and the gynaecologist said she couldn't see anything, so I had an injection and

other medication which did not help. She basically said there was nothing else she could do.

After that laparoscopy, my bowel movements never came back to how they used to be. I now have pain at night, feeling like I need to urinate and feeling like my bladder's never empty.

I am now seeing another gynaecologist who told me that it could not have been mild endometriosis like they told me after my first surgery, it's worse than that and I should have not been told it was mild.

I am waiting for an MRI scan which I am worried about in case it doesn't show anything, I am aware they are not always reliable when looking for endometriosis.

My partner and I want to start a family, so we are now looking at fertility tests, it is a worry with the endometriosis. My partner is really supportive and will make hot water bottles for me because I find the heat helps. And he'll look after me when I'm feeling particularly rubbish.

I am lucky that I have a very supportive family, my mum has come with me to appointments, and I have some doctors in the family who are able to explain test results to me which helps to reduce my concerns and anxiety.

My work gives me reasonable adjustments, and I don't have to go into the office if I am having a flare up. My manager is very supportive.

I also attend a local support group which is helpful.'

Jennifer*

Jennifer says: 'I am a huge advocate for women's health and am now going through the steps for suspected Lupus. I have run half marathons, hosted raffles and had messages from many many girls my age and beyond asking for help and advice. I will never stop shouting about Endo and helping ladies feel empowered to stand up for their health.'

'Well, I wanted to take part in this project because I struggled all through high school. As soon as I started getting periods, I was 12 and I was the first of all my friendship group. At the time, it's really embarrassing.

I never had anyone to turn to and say I've got really bad period pain or I'm feeling like this, so I thought that was normal. I never told any of my friends at school. I went through school going back and forth to the doctors because my mum had said, I don't think what you are going through is normal, but she suffered from painful periods and was told it was normal. So again, there was no education and there was no help, so when we went to the doctors the first time, I was 13. The doctor said *'well, you are only 13, so you're just adjusting to becoming a woman. And this is what happens'*. As a teenager, you're quite impressionable, especially at that age when you're experiencing your period and everything else that comes with that, the hormones, you're at high school etc, so I thought, OK, right, this is normal and it wasn't until I was 20 years old and saw a gynaecologist who said, *'well, it could be endometriosis, but there's no point doing a surgery because nine times out of 10, I don't find it.'* So, he just gave me the pill. Because I'd never heard of endometriosis, I didn't know enough to question what he was telling me, so I just took it for what it was and went away and then lockdown happened.

My journey wasn't smooth at all. I was finally diagnosed at 23, I decided from that point on that I need to shout about it. I share my story on Instagram and I have so many people reply that have either had a surgery and been told it's endometriosis and then have just been left to get on with it, or people that think oh, I have some of these symptoms and I've always wondered, is this normal?

I want people to stop thinking that it's normal because it's not normal and just to have the confidence to go into an appointment and say no, I don't agree with what you're saying, it's so intimidating when you're standing in front of a medical professional, you think they're going to give you all the answers and you do just trust them because that's how it should be. You should be able to walk into an appointment and know and feel trust that they're going to give you the advice and the help that you want.

My work is really supportive, I told them about my endometriosis at my interview, and they were very kind about it. My boyfriend and his family are great; his mum will always ask how I am getting on with my appointments. My mum comes to appointments with me for support and an extra pair of ears! My dad will send me information and research he has found about endometriosis. Thanks dad!

What needs to improve?

'Education.

I remember at college not being able to go to a lesson because I was in so much pain. I went to the toilet and just stood in the cubical trying to zone out to cope with the pain. I thought it was normal because I thought that's what everyone went through and that I was being dramatic about this. It sticks in my mind. I wish someone had said hello, that's not normal.'

Amelia*

Amelia is a mum of three children and works for a local authority.

'You've probably heard stories like mine before, the journey to get actual support and medical attention is very, very long. My first symptoms started just after my second child was born, 12 years ago.

I started getting bloating and irregular periods. I thought, oh, you know, just had a kid. You had one another 16 months before that as well. Come on, just give your body a rest. You know, it's what it is. And then, I started having the stomach bloating and my friend got pregnant at the same time, I was as big as her at like six months pregnant, but there was no child in here. I know there is no child in here. How can this be? And then symptoms just kept progressing. I kept getting low in vitamin D and B12 as well. So just exhaustion, flat out. Obviously regular cycles, heavy bleeding, clots, that type of thing. And then in 2016, I fell pregnant with my third child, and it was the healthiest I've ever was throughout the pregnancies. It was amazing. Love being pregnant. The symptoms started again after I had my third child, the cramping, nausea, my body didn't feel right. It feels like it's

burning and cramping and ripping. So, you just keep going back to the doctor. They just keep doing all your blood tests, going, nope, all these are fine and they don't really work holistically, I had to push to see a gynaecologist. When I finally got through to see a gynaecologist, I was on my knees begging for a hysterectomy, I've done everything. I've done medical menopause. I've gone through having coils fitted which, oh my God, that made things worse for me.

Before that there'd be times when I was coming home from work crawling through the door because I couldn't physically stand up through pain. And it's like, this isn't right. Why does my body keep doing this?

I had already lost my job; I got medically discharged because I had too much sickness leave.

At one point I was bedridden for a year because I lost all mobility through pain. My whole body tensed up, there was sickness, there was bleeding, there was so much going on. The impact it has on your mental health, is just as big as the diagnosis itself. Absolutely, because you're shouting out for pain relief and you're not heard. You're gaslit. Oh, no, just take a couple of ibuprofen, you'll be fine. You're constantly questioned about what's going on in your body and you're made to think, well, okay, if they think it's just this, am I overreacting? Am I looking for diagnosis when actually everyone's telling me my body's fine, but actually it's murdering me from the inside.

When they did the hysterectomy they removed my cervix, fallopian tubes, my womb, but kept my ovaries, both my ovaries. The doctor told me, because you're under 40 years old, you need to keep your ovaries for oestrogen health. And when I woke up from the surgery, I was elated, no pain. For the first time in four years, I was not in pain. I felt amazing.

Six months after surgery, the cyclical pain, the cramping all started to come back. How can I be feeling that? That can't be right. And then I had a big relapse where I had dementia symptoms creeping in. I was having absent like seizures, but they felt like absences, brain fatigue. I think it was a huge crash of hormones, possibly. I don't know. But my GP advised me not to drive. So, I had to take another year off work because the DVLA took my

licence away while they investigated for epilepsy. The stress of not knowing how this would impact my job, would I lose another one due to sickness? Not knowing what was happening in my body, I had short term memory issues, I forgot my son's birthday at one point. My speech was slurred and I kept falling over. I went back to the GP and asked for another referral to the gynaecologist. This wasn't actioned for months, so I had to fight to get that done. My symptoms have deteriorated over time, I have bowel issues, have lost four stone in weight, mobility problems and immense pain.

At one point, my kids become my carers. They washed me, they dressed me. They were the ones cooking, doing the laundry etc. But that is a very big weight on their shoulders to worry about. And as a mother, that's something you never ever want to do for your children. You don't want them to have that pressure. That's my worries not theirs.

It also puts a huge pressure on my relationship with my husband as well. He wants to help and support and do everything to make me better, but then he's so out of control and he can't do anything to make it better.

I don't think you can also understand it until you live it as well. I think it's one of those really, really difficult ones to basically explain how difficult every single day is, how hard that push is, how immense the pain is, because we're not rolling around the floor screaming, crying, pulling our eyes out. We have to go on, life continues. What other option have I physically got other than give up completely? You know us women, we don't do things like that. We're like, nah, come on, we need to get going. The more women in this position have to give more credit to ourselves to rest and not apologise for resting because the more you try and push, the more fatigue, the harder it is for your body to recover.'

Hermione*

Hermione is a mum of three and lives with her family.

'Well, I don't really know what to say. It was quite cut and dry to be fair, I was suffering from awful periods since the age of 14, but as I got older, they

got more intense. I was living with my sister, and I had such a bad period one day, I was on the floor and banging on it for help, it was horrific. My sister got me to the doctor, and I actually saw quite a good doctor who referred me straight to gynaecology. And the consultant I had was absolutely amazing. Obviously, I've heard horror stories but mine was quite straightforward. He listened to my long list of symptoms and said I think you have endometriosis. I had never heard of it. He ended up doing three laparoscopies and told me that I was unlikely to have children, I had suffered two miscarriages when I was 17 and 18 years old. He then did a laparotomy as my symptoms were getting worse and he managed to cut away the endometriosis from my ovary. Within six months I was pregnant with my first child. I then went on to have two further children; I call them my miracle babies!

Then painful periods came back and at one point I was in such pain that I couldn't get out of bed. I was depressed. I had three small children to look after. Hubby was working. I couldn't do it you know, I was doing my best with what I had. The school ended up referring us to social care because my house was a mess.

I went back to see my consultant, I walked in and said, just take it all out, I can't do it anymore. By this point, I was in constant pain every single day. There was no let up. I would take two tramadol, and I'd be on the sofa all day. I couldn't do anything. I had my hysterectomy at the age of 33 years old; they removed everything including my ovaries. I have been pain-free for 10 years.

My youngest daughter is now showing signs of endometriosis, and I think I am going to have a fight to get what she needs and I don't want that for her. I didn't have to fight because I saw the right person.

I think there needs to be a service specifically for young girls, I think something needs to be set up where they can go to see someone that they feel comfortable with, like a clinic or something like that, just be able to say look, these are my symptoms, but then this clinic needs to be educated properly rather than just dishing out contraceptives. GPs need to be

educated properly; thousands of women are actually missing out on their early diagnosis because GPs don't have a clue.

I wanted to get my story out there to hopefully make a difference and to tell other women that I know hysterectomy is not a cure. I know that, but it cured me.'

Mena*

Mena lives with her family and works for a local charity.

'I'm 53. I had a hysterectomy six years ago. The doctor left my ovaries in, I begged him to take them, I had had my three children, I was done but he said no because leaving them in protects against heart disease. It took a year for me to recover from the hysterectomy; I was really unwell and had lots of complications.

And then it's all come back as if I was still having periods. I've been in hospital twice in the last couple of years due to infections within the endometriosis. I end up going to hospital and being put on IV antibiotics. And even then, you're treated like a complete and utter inconvenience, like you're making a fuss. I'm quite a tough cookie and if I can't sit on a chair due to the pain, that's when I know I have to go. I have had an MRI scan, and they found endometriosis on my bowel and bladder, I was referred to the endometriosis specialist at Colchester, waited a year for an appointment which got cancelled the first time, you pin your hopes on the appointment and then it doesn't happen. I finally saw the specialist's registrar who asked me if I was sure it was endometriosis, was it irritable bowel? I cried in the car after that appointment and thought what's the point? I did get to see the specialist at my next appointment, and he started me on Ryeqo, it's a new drug that basically puts your system into menopause because I still have my ovaries. I'm still growing cysts. I've got haemorrhagic cysts that burst, and it's just a relentless cycle. The pain is unbelievable. But the drug isn't doing anything for me. I was so ill over Christmas, if I had the option, I wouldn't have got out of bed for 2 1/2 weeks,

but that's not an option. I've got three children with additional needs, so I don't have a choice, and you keep going.

I was due to have an appointment today, but it got cancelled...I am nearly out of medication and because it's a trial, I can only get it from the hospital, I have to order a month in advance. So, I've got no idea what's going to happen. It's a complete and utter shit show is the honest answer. And there's no answers. Possible surgery, but there is the risk of a stoma because of how much is on my bladder. They can't get to my ovaries so it's this for the foreseeable. But the big fear is I think for women, probably there's lots of ladies like me and there'll be lots that are in a lot worse. I mean, I'm lucky in the sense that I'm actually really strong and I do keep going, but I shouldn't, but I do. But there's some people that just can't do that or they haven't got support. I'm lucky my husband's brilliant.

I see it in my 14-year-old daughter already, she's on medication to reduce how heavy her periods are. And I'm like, this isn't okay, you know, because this is our future generation. They shouldn't have to go through what we've been through.

There's just no empathy. And I think that's the worst bit. There is no empathy.'

Helen*

Helen lives with her partner.

'You get used to not feeling 100%, it becomes the norm. I have endometriosis, adenomyosis and IBS.

My periods started when I was 9 years old and my symptoms started at the age of 11. I was told that the pain was all in my head, I was being dramatic and that women just have to deal with it. I had to have time off school due to the pain and was prescribed the pill at 14 years old. Misdiagnosis makes you feel like you are going mad.

I have seen NHS gynaecologists and paid for private treatment. When I was 17 years old, I was told that if the pain was that bad then I should have a hysterectomy. A year ago, I had an MRI scan which showed that the endometriosis had grown back on my bowel, but the consultant said they wouldn't operate until it had perforated. No discussion, I was discharged and now I am back on the waiting list again.

I tried to get pregnant for our years, was told that I had to try for five years before starting any IVF treatment on the NHS. I found private support/advice around diet and herbal treatments and now I am just over three months pregnant. But at my first appointment with the midwife, she had no idea what endometriosis was.

There needs to be more funding for research, more specialist consultants and more information for young women.'

Lindsey

Lindsey wanted to share the experience of her most recent appointment.

'I had a follow up (which was supposed to be Oct/Nov 2025, but I got missed) today (February 2026) and I'd love to share the experience.

My condition is a little complex (endo/adeno/fibroids/lost coil that I didn't want in the first place/A&E visits) but after today I have little choice but to get a second opinion and I'm going to have to pay private as OH are now involved at my work. I'm under Southend for Gynaecology but the treatment I've been referred for (ablations) could be extremely dangerous without scans even an MRI and I'd love the discussion. Totally rushed and dismissed today and it's belittling and disheartening.

I'm 43 next month. It's completely ruined my life with fainting, vomiting, loss of bowel control, loss of blood pressure, radiating leg pain, back pain, stomach pain, muscle spasm, (cracked my coccyx at 14 due to fainting onto concrete, resulting in degenerative disc disease at 30) to mood swings, mental health, inappropriate gynae's and all sorts the list is endless.

In the past 30 years I see very, very little change in endo/adeno conditions or the treatment plans.

Thanks for listening at the very least and fighting for us.'

Monica

Monica is the founder of Women's Health Hope: [Womens Health Hope – Womens Health Hope](#).

Their website says: 'Women's Health Hope is an independent charity dedicated to **supporting, advocating** for, and **educating** about women's health. Our mission is to shine a light on the unique challenges women face and create a safe space where no one feels alone in their journey.

Our founder, Monica, knows firsthand the struggles of living with under-recognised and misunderstood health conditions. After battling symptoms for 17 years—often feeling unheard and dismissed—she was finally diagnosed with **lichen sclerosis, endometriosis, and adenomyosis**.

"For years, I felt isolated in my own body, constantly questioning my pain as all my test kept coming back clear. I had no one to turn to who truly understood. Receiving my diagnoses was a long and difficult process and coming to terms with them is an ongoing journey. This experience inspired me to create change. Women's health needs greater support and recognition. The physical, emotional, and social impacts of these conditions are profound. No woman should feel isolated or unheard. Together, we can build a community to support and uplift each other." – Monica, Women's Health Hope's Founder.'

Monica lives in Suffolk but as they do not have an endometriosis specialist she was referred to Colchester Hospital. Monica has thoracic endometriosis, so she needs specialist care/treatment; currently there is only one thoracic endometriosis specialist in the UK based at Guys and St Thomas Hospital in London.

'We know our bodies better than anyone. I suffer with medical PTSD due to my experiences, I have been told that my pain is not real, that I am faking it etc. Even though I am currently under a consultant that I chose, I still have anxiety when dealing with appointments, surgery, medication etc. I am in pain every single day. Some days I am able to run my charity from my bed but there are other days when I can't even do that.

I feel like I am being let down, we have to do better, so many health professionals don't know about endometriosis. It's complex.

One woman told me that she was told by the hospital that she couldn't have an MRI scan due to funding, so they did her operation without it, the operation took five hours because they didn't know what they were going into and she was moaned at by staff because of this.

I have been advised to attend A&E if my thoracic pain is different to normal. I have been in an ambulance when a nurse came out and said 'she fakes this every time'. I couldn't breathe because of the pain and was so scared. The lack of compassion is unbelievable at times.

I have met my local MP to see how he can support us in parliament, but when I have tried to arrange a follow up meeting, I have had no reply. I have emailed him many times and nothing.

If my endometriosis had been found earlier, then it wouldn't have spread. I am unable to fly again and have been told no more pregnancies as my diaphragm will not cope with a growing baby or giving birth.

Women need a safe space and to be supported.'

Perspectives of partners/loved ones.

It was important to hear the experiences of the loved ones who support these women and witness them trying to cope with the physical and emotional/mental impact of endometriosis.

Friends/family/partners/children often become carers to these women and the impact on their lives cannot be underestimated.

Ava* asked her partner how her experience of endometriosis has impacted him:

'I asked him how me having endo has impacted him?'

He started by saying it doesn't in many ways but the more he thought about it the more he had to say. When we met, I was probably at my most unwell and I was undergoing surgery. He found this hard as there was very little, he could do to support me and didn't really understand what was going on. He was also so frustrated and disappointed that my bicornate/septate uterus had not be spotted or treated so I had a least three rounds of IVF that would never have worked. He wanted to take the world on and lodge formal complaints, but I honestly just didn't have it in me and wanted it all over with.

He said now that we have a really open conversation style, and he knows he can ask me anything so has since learnt a lot about endometriosis and other conditions such as menopause and perimenopause but most importantly what to do when I am unwell. This Christmas I had a bad flare up and he know that meant I didn't really want to go out, wanted pain killers, hot water bottles and chocolate. All of which he provided constantly until I felt better. He knew that this would not the case before he met me and he wouldn't have known about this or what to do and probably wouldn't have asked.'

What could be done differently?

'I asked about education in school and he had a lesson on periods and condoms and that this was all together and then after this the girls went off and so did the boys. It was a science lesson, and they didn't talk about anything other than the 28-day cycle and assumed this was the same for everyone.

It was not talked about all the time but having close female friends they would say they are on their period so didn't want to go swimming or later plan holidays around that time of the month. It wasn't discussed regularly but equally wasn't taboo.'

If you had a magic wand?

- Better education in schools that focused on how different things are and not necessarily all the information but how to access good information.
- Merchandise for men – leaflets to give to dads, brothers, boyfriends, friends from school or the clinic.
- Dedicated spaces/groups/events where they can have guest speakers or people with lived experience that can answer questions on periods, menopause, endometriosis, post-natal depression, pregnancy, polycystic ovaries. Anything to do with ‘women’s problems’ that they can ask in a safe environment without worrying about how they come across or sounding dumb.
- Better awareness raising like you have with breast cancer awareness.

Anna*

Anna shared her experience of supporting/caring for her partner:

‘I’m writing to share my experience of living with my partner who suffers from endometriosis, and how this condition affects not only her life but mine as well.

Every month, she struggles severely with pain. It completely takes over her ability to function normally, and during those times I feel incredibly helpless. There is very little I can do to ease what she is going through and watching someone you love be in that level of pain, repeatedly, is emotionally draining.

The condition doesn’t just affect her health – it affects our entire lives. We are unable to make future plans with confidence. Before booking anything or committing to events, we have to calculate whether she is likely to be on her period. Even then, slight changes in timing can mean cancelling plans at the last minute. It impacts holidays, social events, and even simple

commitments. We often avoid saying “yes” to things in advance because we just don’t know how she will be.

It also affects our home and social life. There are times we can’t have family come round because she is in too much pain. Our relationship has to work around her symptoms, rather than us being free to live normally.

Work is another major stress. Her employer frequently pulls her into absence investigations due to time off related to her condition. This adds anxiety on top of the physical pain. She receives no sick pay, which creates financial strain and additional pressure. Instead of being supported for a chronic medical condition, she feels scrutinised for something outside of her control.

On top of this, the process through the National Health Service has been extremely slow. There are months between appointments, which leaves her in limbo – in pain, waiting, and without clear progress. The waiting and uncertainty make it feel like there is no urgency around a condition that is severely affecting her quality of life.

Living alongside endometriosis means living with unpredictability, stress, frustration, and helplessness. It impacts both partners, not just the person diagnosed. I hope sharing this perspective helps highlight the wider impact this condition has on relationships, work, mental health, and everyday life.

I do hope this helps future women who struggle and their partners. During the worst episodes, especially through the night, I am the one caring for her – managing medication, refilling hot water bottles, helping her move when the pain becomes overwhelming, and monitoring her when she feels faint or unwell. There are nights where neither of us sleep. The pain keeps her awake, and I stay awake to make sure she is safe and supported. Over time, this has left me sleep deprived and physically exhausted myself. On particularly severe months, I have had to leave work to care for her because she has been so unwell – sometimes fainting or unable to stand properly. It puts pressure on my job as well, but in those moments, her wellbeing has to come first. The responsibility can feel heavy, but it is not

something I would ever ignore – it is simply the reality of loving someone with a condition like this.

Thank you for taking the time to read my experience.'

2.4 Essex Support Groups

There are currently two support groups in Essex for endometriosis, one in Rayleigh and one in Colchester. There are no face-to-face support groups in the west of the county.

I was welcomed by both groups to attend one of their meetings. Both groups were really relaxed and friendly, the women who attended talked about their experiences, some of them were going through their journeys of either trying to get a diagnosis or in various stages of treatment. Many talked about how they managed their symptoms, where they found information/advice or the latest research. It was easy to see how much benefit the women got from these groups, being able to share their experiences and knowing they weren't alone was a big help to them.

Rayleigh Support Group

Donna, Katie and Sarah from the Rayleigh group took part in a podcast as part of the Healthwatch Essex Hidden Voices series. They wanted to help raise awareness by talking about their experiences of endometriosis, the difficulties in getting help, diagnosis, treatment and ongoing care/support, the reality of trying to live with endometriosis and how it impacts their lives.



'It's not just a bad period!': Living with Endometriosis

You can listen here: [Hidden Voices • A podcast on Spotify for Creators](#).

The Rayleigh support group was started last year by the local Primary Care Network. You can find out more about the group here: [Endometriosis - Rayleigh & District Primary Care Network](#).

Mary

Mary is the population health nurse for the PCN:

'The endometriosis group started in March 2025 coinciding with the awareness month. The idea was sparked due to members of staff suffering with endo themselves and myself having family members with it which gave us the insight and understanding of the lack of support in general for those with endo.

We ran a report to identify those who have it and then sent texts inviting them to come along to a peer support group as well as sharing on social media and putting up posters.

Our first meeting took place in a lounge restaurant, and we had 4/5 people turn up and shared their experiences and difficulties they have faced.

We then managed to secure space at The Hive at Rayleigh Baptist Church which was more private and calmer, and enabled people to share their stories more openly and in a confidential way.

More people have started to attend, and we will now be starting to alternate between daytime and evening meet ups to enable more people

to come which has been a result of collaborating with members of the group.

The group has a good balance of peer support and professional support, it has enabled some members to get appointments when needed and encouraged, uptake of cervical screening which they have previously not been able to manage and providing valuable collaboration towards our trauma-informed cervical screening project.

I am proud of the members of this group and how they support one another, and also very proud of the team with keeping this going especially [@CAIGER, Niki \(GP HEALTHCARE ALLIANCE ASHINGDON\)](#) [@LAMBOURNE, Faye \(GP HEALTHCARE ALLIANCE ASHINGDON\)](#) and [@QUINN, Tracey \(GP HEALTHCARE ALLIANCE ASHINGDON\)](#).

I hope we can continue to grow this group and raise awareness as it has provided invaluable support to those who already attend.'

North Essex Support Group (Colchester)

The north Essex support group is part of the Endometriosis UK network and is run by volunteers Christianne and Sheree for the last nine years. You can find out more information about the group here: [Support Groups | Endometriosis UK](#). They say:

'Our support group provides a safe, supportive, positive and friendly environment for sharing experiences.

It offers the opportunity to share, be listened to and to know that you are not alone.

There is a mixture of informal meetings and talks from guest speakers who offer additional information on topics that are of interest to the group.'

Christianne

'I know first-hand what it is like to live with endometriosis, to feel unheard, exhausted and overwhelmed while searching for answers. I experienced debilitating pain from my teenage years and, after ten years of being dismissed and countless medical appointments, I was finally diagnosed with endometriosis.

What followed were years of invasive surgeries which brought little relief and had a significant impact on my quality of life. I then made fundamental, practical and sustainable lifestyle changes, particularly around nutrition and self-care, and my symptoms improved dramatically, although further complications eventually led to a hysterectomy.

When a close family member was diagnosed with endometriosis some years later, I was deeply disappointed to see that diagnosis times, understanding and treatment pathways had changed very little. This was a turning point for me and reinforced how vital peer support, shared experience and accessible information are for those living with the condition.

Since 2017, I have co-led the North Essex support group for Endometriosis UK, creating a safe, informal and welcoming space where people affected by endometriosis can meet others who truly understand, feel listened to and supported, and realise they are not alone, whatever stage they are at.'

Sheree

'I was diagnosed with endometriosis, fibroids and PCOS, in December 2013. I did not know what it was or how this would impact on my life both physically and emotionally. I felt silly that as a woman I had no idea what this chronic incurable illness was and how I was going to manage and move forwards.

I spent lots of time in recovery from my operations, researching and I attended a day with Endometriosis UK in London in 2014. This was inspiring and reassuring, and I realised how much I wanted to spread the word.

I now feel ready to support other woman who may have felt like I did, so they do not have to suffer in silence or go through what I and many other women have had to.'

The stories told by the women who attend these groups share many commonalities. They struggle to be heard by health professionals, the waiting time to be referred and then to see a specialist, the lack of specialists, lack of follow up after operations/treatment, poor communication, accessing private treatment if that is an option for them, trying to find ways of dealing with the pain and how that impacts their day to day life and relationships both personal and professional.

The north Essex group has a good communication link with the endometriosis specialist at Colchester; he has recently written to them to explain the various factors that affect the waiting time to access the service.

Knowing that the waiting list is so long is hugely frustrating but having that clear communication and the reasons why can be helpful for women to be able to manage their expectations of when they could be seen and maybe look at other possible options including private healthcare if they can access this.

3.0 Key Findings

Many of the women who responded to the survey said that their symptoms started when their periods did, and they thought that what they were going through was normal. By the time many of them either told someone else what they were experiencing or first saw a medical professional for answers, they had already been suffering for many years. The battle then began of trying to be heard by health professionals, getting answers, referrals, advice, treatment, just getting help and being believed. The physical, mental and emotional suffering for these women is shocking to read, every single aspect of their life is/has been affected by endometriosis.

'I went to the doctor weekly for over six months with symptoms that were getting worse before a male doctor told me he'd refer me for a scan for "reassurance" because I was getting "hysterical" and "wasting everyone's time".'

'I think my periods were always pretty bad from when I started having them - potentially more painful than the usual period (not that I would have known that.) So, it possibly started from the age of 13, however, it wasn't until I was 17 that I really knew something wasn't right and started going to the GP for advice.'

Being heard by health professionals

'Gaslit' was a word that was used by several of the women when talking about their experiences with health professionals. Many felt they were not listened to when they first talked to a GP about their symptoms, many were brushed off as being 'too young' or 'it's just a period' or 'this is part of being a woman'. Just the first stage of being listened to by a GP was a struggle for many women, only a few of the women were referred to gynaecology when first going to the GP for their symptoms. Most had to return to the GP numerous times asking for help, this sometimes led to referrals to different

specialities and at times misdiagnosis. But often women were sent away without any real help or advice. Some did have positive experiences with health professionals but unfortunately this was not most women's experience.

'The mental effect of not being believed runs deep and I don't trust many health care professionals.'

'I always thought it was in my head as I kept being told it was just a bad period. Just take contraception or have the coil.'

'I often experience imposter syndrome- after years of being made to feel that endo is 'just period pain', so I often feel like a burden or an exaggerator.'

'Just to get an appointment with a GP nowadays is a difficult task, but to then have a GP that listens to you and is willing to believe and investigate further? That's basically a miracle. And when I was first seeing doctors after my A&E in 2021, a lot of them were dismissive because of my age, claiming I'm "too young" to have anything wrong with me. They refused to do tests. They then wouldn't share the results of the test or lied about the results. One male doctor even tried to 'mansplain' what a period was to me in order to dismiss my symptoms as just a bad monthly. I've been told I'd been referred places only to be told I hadn't after a year of waiting. I once saw a great gynaecologist during another A&E visit and she told me to ask my GP to refer me to her, and my GP claimed I was lying about the whole thing. For almost 3 years I was being told that it was all in my head. It really, really destroyed my mental health as I knew that what I felt was physically real, yet I had nowhere to go to for help.'

'I always felt as though I was being brushed off and made to feel like it was all in my head or normalising my symptoms.'

'I went to the GP several times and would be told they didn't know whether to refer me to a Gynaecologist or a Gastroenterologist, so no referrals were made. In the end a locum GP decided to refer me to both.'

'I have felt listened, but I have had to push for answers. From the first time I went to the GP about this, it took me 9 years to get a diagnosis. The process can be exhausting as you feel like a hypochondriac and like it is in your head, when it isn't. Unless you advocate for yourself, it's easy to not get a diagnosis.'

The physical and mental suffering

As well as the immense physical pain that women experience, they also talked about questioning their own mental state in connection to that physical pain, 'is my pain worse than others? am I being dramatic?' Women shared about the mental impact endometriosis has on them, many have felt suicidal, suffer with anxiety, low mood, depression and can become isolated. The way they view their own bodies is also affected, many are unable to wear clothes they want too, they felt unable to even look at their own bodies.

'The endo belly is a huge thing for me I have cloths that range from my normal size 12 all up to 16 as my stomach bloats that much. I hate looking at myself in the mirror as I hate what I see in the mirror.'

'My dress style has changed as I can't wear tight clothes anymore. I always have to have a toilet nearby as I also have IBS. I don't really go out.'

'I have been very suicidal at times and have not wanted to wake up to just experience another day of unbearable pain.'

'Mentally - completely changed me as a person - I have suffered because of it.'

'On very painful days I would stay curled up in bed, taking far too many co-codamol's.'

'Really low mood, not feeling in control of my body.'

'Over the years there has been times where I have felt afraid to leave my house.'

'Painful uncomfortable stomach. On occasion it hurts to wear any clothes on it, meaning I don't like leaving the house.'

'Endometriosis takes so much away from you. Each time symptoms return after surgery, it feels like grieving the person you used to be. It's a relentless cycle that impacts every aspect of life.'

The wider impact

Women have lost jobs/careers or been unable to find employment that could be done around the endometriosis, relationships, friendships, family, impacted their time at school/college and the ability/option to have children. Planning/attending social events, being able to do activities with their children, the ability to make any basic plans in life is affected by this condition. Some women said their employers were helpful and made reasonable adjustments where possible, but others had no support at work and ended up having to leave their jobs or being dismissed due to the amount of time they had off sick. The financial pressure is then another source of stress and worry for these women.

'It's meant I couldn't go to school, then impacted my degree. It's made me change careers. This means financially I struggled. I find it very hard to deal with and have weekly therapy. I've had 3 operations so far. I am now infertile'

'There is an expectation to continue as 'normal'—working, caring for family, managing a home, and maintaining hobbies—which is exhausting and often impossible.'

'Physical symptoms have led to inability to work or exercise further leading to chronic depression and anxiety. At one point suicidal tendencies.'

'Unable to partake in PE so made to walk around the netball courts until I passed out. Missed special occasions, had to walk out of weddings etc. Flair ups that caused huge fevers and trips to A&E. Flooding out at college/work. Miscarriages.'

'My line manager is aware at work, but I currently work mainly from home so have been able to manage symptoms whilst still working.'

'Employer understands but still under HR review due to company policy.'

'Employer was awful so I left and retrained so I could work for myself.'

'My manager at work is supportive in allowing me to attend appointments but I do feel pressure not to have any sick days.'

'My work has been supportive; I have had an occupational health assessment and have reasonable adjustments in place for bad days/flares.'

'I work as a teacher, and my workplace do their best. The bottom line is that endometriosis can cost you a career.'

The people around the woman

Partners/friends/family are hugely affected by watching a loved one trying to cope with endometriosis and often end up becoming their carer. The support network around a woman is so important but some of the women did talk about people in their lives struggling to understand what they are going through. Many didn't like to burden friends/family so felt they weren't always able to talk about it.

'I have one good friend who does their best to understand. And I have my son, who even on my bad days, still cares deeply about me. Who loves me even if I can't take him to the park.'

'My fiancée is my carer and is very supportive, my family is also very supportive and the friends I have told so far seem to sort of understand and are supportive but maybe don't seem to quite get how bad it is.'

'I have my partner, who tries his best to be supportive and is very open minded about the condition, and is also very angry about how women are not taken seriously. He just hates that he can go to the GP for a minor thing and get treatment instantly, including a follow-up check-up, whilst women

have to jump through so many loopholes. Whenever I have a doctor's appointment, he always moves his work around to accompany me. My best friend is also understanding and direct about it, which helps, as some people like to skip around something that is such a huge part of my life. As for my family, it's a hit and miss. I don't have a big family, and I know they feel sorry that I'm going through this, but most of them don't know how to support me and don't accommodate my needs, which means I either have to completely put all my needs aside just to hang out with them or be left out from some events. The former isn't good for my physical health, and the latter hurt my mental health.'

'My partner has been very supportive and tries to learn about best to support my symptoms. I haven't shared it with family.'

'I have a best friend who also has endo so I feel support from her, but she has a family to worry about. I get very little support from family and don't want to burden the few other friends I have.'

'My family especially my husband has been an absolutely amazing, it's not just me this affects or changes my life it's his too. I've lost friends whom I was closer with before all this due to me having to cancel plans and not drinking as had to change my whole life. I've got friends who also have endo and I've got friends who don't but don't judge me for cancelling or having to change my whole age my lifestyle they take me how I am good and bad days, just means my circle is much smaller than used to be. I have some endo support groups online which have been helpful. I work and my employer is great due to having to take off for multiple hospital appointments, and two surgeries, the biggest thing is I don't get sick pay so financially, we are on the breadline.'

'My fiancé has been absolutely incredible, there for all emergency hospital visits, ensure I stay home when too ill to work. My sister has also been my rock, being there for my children when I physically can't get out of bed.'

'My husband struggles at times because he feels helpless—he cannot take away the pain or make things better. Our intimate relationship has been non-existent for three years because the pain is too severe, which has

been hard for both of us. He also bears the brunt of my fluctuating emotions and anger caused by debilitating pain. Endometriosis puts immense strain on marriages, and many do not survive the turmoil it brings. Even when you mask symptoms, partners can believe you are “fine,” which adds to the disconnect.’

Support

Many women have good support networks which included partners, family, friends, online support-charities and social media and face to face groups. Some felt they didn’t have any support, others didn’t feel able to join online or face to face groups due to anxiety, timings of face-to-face groups or able to sit comfortably for a length of time. Many of the women talked about other female family members having endometriosis so having someone else who understood what they were going through really helped.

‘I have friends who live with endometriosis, and they are fantastic at lifting me up on difficult days or helping with the kids when I cannot function. I am part of online and face-to-face support groups, which help validate my symptoms and experiences because everyone shares similar struggles. However, while these groups provide emotional support, they cannot reduce the physical pain or replace the medical attention I desperately need but cannot access.’

‘Very little support. Single person. Few family members. Teacher so unable to work from home. A couple of good friends who help when they can.’

‘Family are very supportive and have a sister with the same condition helps. Don’t attend any support groups.’

‘My friends and family are incredibly supportive and understanding with my conditions. My fiancé has learnt so much about the conditions to try to understand and help me further & even went on to run a half marathon to raise money for Endometriosis UK.’

'I have friends and family who can empathise and I am part of the northeast Essex endo group on Facebook where I've often posted for advice.'

'I've lost friends and have no family in my life. I have a 3-year-old son who's my whole world. I'm in a few Facebook groups for those with endometriosis which is supportive in knowing that I'm not alone.'

'My husband, one of my friends- but a majority don't really get the extent of what I go through. My employer is fantastic. But I shield my parents from knowing too much- as I don't like them to worry. I do sometimes follow stuff online- but often find it all very negative.'

'I found online resources helpful, but these weren't available in the earlier years. I have delivered workshops with a colleague who also has endometriosis and this has connected me with others too.'

'I have only had support since finding the charity Endometriosis UK as there was nothing when I was diagnosed a lot of health care professionals don't know a lot about endometriosis.'

'I was recently invited to an NHS support group but it's Friday daytime and I work so can't go.'

'The TikTok community has been my biggest support and place for information.'

'My friends are great and totally understand my limitations. My partner and Mum are extremely understanding and take it in turns to help me. I don't have any support from anyone with endo as no one I know has it, and there aren't any groups local to where I live.'

'I attend the recently established support group in Rayleigh and have followed Endometriosis UK and other groups on social media.'

'Online support group (I find the in person one in Colchester quite depressing and the seats are uncomfortable). Friends have been understanding but drifted away. Family similar. Good partner and employer.'

'I use a lot of online forums where I have made friends, but my sister also has endometriosis so she's a great support.'

'I wish people knew that Endo was for life. Not to sound depressing or hopeless. Life can get better with Endo. But there isn't a cure. Everyone I meet is always telling me to get better soon (which is fine), but it's when they're persistent that there's this new drug that has like 100 side effects but might cure me that it becomes too much. Or when they keep questioning Endo-sufferers about what they plan on going with their lives or expecting things to go back to normal after they have a surgery, or tell them to just get pregnant, when the reality is that their lives aren't going to drastically change. Surgery isn't the miracle we're hoping it is. When I was waiting for my surgery, everyone around me was so optimist that this was it. That I was basically going to come out a different person after. It felt scary. No one wanted to face the possibility that things weren't going to just magically improve overnight. -- That's where I think we need more awareness, so that there is less pressure on people suffering with Endo. We have to be realistic. Hope is good, but too much of it can be crushing when it becomes delusional.'

4.0 Conclusion and Recommendations

'It's not just an NHS problem, it's an everybody problem.'

On 4th March 2026 the Women and Equalities Committee released a report urging the Government to commit to a range of measures to support girls and young women with menstrual health conditions including endometriosis.

The Committee made a total of 43 recommendations to Government, which included how the Government must improve endometriosis and menstrual health care. You can read the full report here: [Reproductive health conditions: girls and young women](#).

Some of the recommendations were:

1. Calling on the Department for Education to develop resources and guidance for teachers and other school staff to embed menstrual health awareness and support at a whole school level.
2. Reduce diagnosis times for reproductive health conditions such as endometriosis.
3. We urge the NHS to record the pain history of women undergoing procedures so that their needs can be prepared for.
4. A substantial increase in research into menstrual health conditions is long overdue and would represent a huge stride forward in recognising the impacts these conditions have on the lives of women and girls.

Women are being let down by the NHS and society in general in many aspects of women's health, but the lived experience shared by the women who have taken part in this project is at times, extremely shocking. The lack of awareness and understanding, not just from health professionals but from the whole system is unacceptable. Women feel unheard, gaslit and are generally left to deal with debilitating pain that effects every aspect of

their lives. It is not acceptable that in 2026 that it is now taking over 9 years for women to be diagnosed with endometriosis, this rises to 11 years for women from ethnically diverse communities.

Being listened to

- The 'basic' act of being listened to by medical professionals needs to improve.
- The recently announced primary care initiative, Jess's Rule, may help towards improving women being heard when they are returning to the GP with the same symptoms:

Jess's Rule is a primary care initiative to encourage GPs teams to rethink a diagnosis if a patient presents three times with the same symptoms or concerns, particularly if symptoms unexpectedly persist, escalate, or remain unexplained.

*Jess's Rule asks GP teams to '**reflect, review and rethink**' if a patient presents three times with the same or escalating symptoms.*

Find out more about Jess's rule here:

[NHS England » Jess's Rule: Three strikes and we rethink](#)

Basic communication

- Clear and honest information regarding referrals and wait list times needs to be improved. When a referral is made to gynaecology there should be a letter/email sent to the patient explaining the wait times and any advice/support signposting that could be given regarding 'waiting well' for the appointment.
- Improved follow up services/appointments following treatment/operations instead of being discharged with little to no further monitoring.

Education

- Awareness sessions in schools'/colleges for all genders to help raise awareness and share information.
- Develop training sessions for all medical staff, especially those in primary care as they are the first stage of accessing NHS services.
- Information sessions for employers, how they can better support employees with endometriosis and those who care/support them.

Support/Advice

'Women need nutritional help, mental help, physical help, and to be treated as a whole.'

- Earlier signposting to organisations who can offer support/advice.
- The possible development of a face-to-face peer support group for the west of the county—more research needed into the need for this as response from this part of the county was lower compared to the others.

5.0 Support/Advice/Further Information

endometriosis-uk.org

[Home | The Endometriosis Foundation](#)

Royal College of Nursing [What is Endometriosis publication.](#)

[NHS Endometriosis information page](#)

[THIS IS ENDOMETRIOSIS](#) BAFTA award winning film 2026.

[Womens Health Hope – Womens Health Hope](#)

[Characteristics of women with an endometriosis diagnosis in England – Office for National Statistics](#)

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