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Women’s Health

Stories of women’s health experiences in York

healthwatch
York

Contents

Content warning: These stories include references to misogyny, mental ill-health, distress, self-harm, violence, suicidal ideation, birthing experiences, miscarriages, and discrimination. Please only read these when you feel able to.

Key

Blue background = story shared with Healthwatch York

Yellow background = story shared through York Disability Rights Forum (YDRF)

Pink background = concern shared by other partner organisations

Acknowledgements:

Thank you to all the women who shared their stories with us, and allowed us to share them in this report. All names have been changed. Thanks also to our partners including YDRF, York Women's Centre, and the York Branch of the National Osteoporosis Society.

Cover photo by the Reproductive Health Supplies Coalition via unsplash

Executive Summary

This report shares local women's experiences of health and care across the life course. We bring these stories together to try and provide a more complete picture of women's health in York.

Overall, women want to be listened to. Collectively and individually. Many women talked to us about their poor experiences in seeking help for health issues. They want to see improved recognition of, and support pathways for, long term conditions. These include:

- Endometriosis and fibrosis
- ME / CFS
- Fibromyalgia
- POTS
- Ehlers-Danlos Syndrome
- Osteoporosis
- Pre-menstrual dysphoric disorder

Women also shared their concerns about issues relating to menopause, especially early menopause. They reported concerns about dismissive attitudes, and a lack of consistency about the support available. But they also wanted to highlight that women continue to need good health and care support after menopause.

A number of women also raised concerns about 'labelling' mental health diagnoses mainly given to women. Those mentioned include:

- Borderline Personality Disorder (BPD)
- Emotionally Unstable Personality Disorder (EUPD)[1]
- Paranoid Personality Disorder (PPD)

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[1] BPD and EUPD are essentially the same diagnosis.

Many people now disagree with these as diagnoses, and point to societal factors underpinning the problems people experience[2]. It is important to note however that some women felt getting a diagnosis was helpful, and validated their experiences.

We are committed to ongoing work with women in the city to further explore the issues they experience in living with long term conditions. We hope others find this report useful in identifying commitments now to improve the future for women in our city and beyond.

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[2] E.g. https://www.mind.org.uk/information-support/types-of-mental-health-problems/personality-disorder/why-is-personality-disorder-controversial/

A message from our Chair

Healthwatch exists to be the voice of local people in our health and care system. We wanted to highlight what we have already heard from women across our area. We hope that collecting them together can help inform:

1. The work of Humber and North Yorkshire Health and Care Partnership in developing Women's Health hubs.
2. Action plans following the women's health needs assessment being led by the Public Health team at City of York Council.
3. Work across York and North Yorkshire to improve support for women's health.

This report is a collection of women's stories. They brought to us their experiences, the barriers they face, the good that they encounter and the things they believe would make life better for women.

We were established based on a simple belief – that the best people to help shape health and care services are those that use them. Indeed, we believe sometimes the only power we have to effect change is the power of our life stories. We hope these stories raise awareness of what women encounter throughout their lives, and help shape the work mentioned above to improve their daily experience.

Background

Women make up 51% of the UK population. They generally live longer than men but spend more time in ill health. It is widely accepted that there is not enough focus on health conditions that only impact on women, or how conditions that affect both men and women may present differently and have different outcomes.

National strategy

In 2022, the UK Government published its first strategy focusing on women's health inequalities[3]. The 10-year 'Women's Health Strategy for England' set out commitments to improve the health and wellbeing of women and girls and deliver better health outcomes. The strategy aims to reduce gender-based health inequalities. The priorities identified within it are based on responses to the call for evidence that preceded the new strategy.[4]

In the operational guidance for 2024/25, NHS England set out a requirement for Integrated Care Boards (ICBs) to establish women's health hubs by December 2024. Every ICB received £595,000 to support this work[5] regardless of the population size they serve. This varies from 520,000 to around 3.1 million people. These hubs can be virtual, and do not have to cover the whole ICB area. They must provide two of the core services from the core service specification[6], namely:

- menstrual problems assessment and treatment, including but not limited to care for heavy, painful or irregular menstrual bleeding, and

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[3] https://assets.publishing.service.gov.uk/media/6308e552e90e0729e63d39cb/Womens-Health-Strategy-England-web-accessible.pdf

[4] https://www.gov.uk/government/calls-for-evidence/womens-health-strategy-call-for-evidence/outcome/3fa4a313-f7a5-429a-b68d-0eb0be15e696

[5] https://www.england.nhs.uk/long-read/womens-health-hubs/

[6] https://www.gov.uk/government/publications/womens-health-hubs-information-and-guidance/womens-health-hubs-core-specification

care for conditions such as endometriosis and polycystic ovary syndrome
- menopause assessment and treatment
- contraceptive counselling and provision of the full range of contraceptive methods including LARC fitting for both contraceptive and gynaecological purposes (for example, LARC (long acting reversible contraception) for heavy menstrual bleeding and menopause), and LARC removal, and emergency hormonal contraception
- preconception care
- breast pain assessment and care
- pessary fitting and removal
- cervical screening
- screening and treatment for sexually transmitted infections (STIs), and HIV screening

Cervical screening

NHS England set a target to eliminate cervical cancer by 2040, despite declining numbers of women taking up cervical screening over the past 20 years. In 2023-24 Healthwatch England and local Healthwatch, including Healthwatch York, undertook research into the barriers that prevent women completing cervical screening. The key findings were strong support for home testing, with many reporting their concerns about physical discomfort, embarrassment at undressing in front of health professionals, and a belief you don't need screening if not currently sexually active[7].

Maternity experiences

In 2022, the Black Maternity Experiences survey was completed by Five X More[8]. They received responses from 1340 women. This shone a light not just on the indisputable fact Black women experience

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[7] https://www.healthwatch.co.uk/report/2024-09-16/cervical-screening-my-way

[8] https://www.nhsbmenetwork.org.uk/wp-content/uploads/2022/05/TheBlackMaternityExperienceReport.pdf

significantly poorer maternal health outcomes, but also the potential causes – racist attitudes, a lack of knowledge and assumptions made about Black mothers – for their negative experiences. More than half reported facing challenges with healthcare professionals, with 43% feeling they were discriminated against. 42% reported the standard of care they received whilst giving birth was poor or very poor. The same number, 42%, felt their safety had been put at risk by professionals either during labour or in the recovery period.

The Care Quality Commission (CQC) completed an annual survey of maternity experiences in 2024. Many people reported positively about their interactions with maternity staff while pregnant[9]. Most of those surveyed (83%) said that their midwives 'always' listened to them, that they were 'always' spoken to in a way they could understand (88%), and they were 'always' treated with respect and dignity (87%). A similarly large proportion of respondents (80%) said they were 'always' involved in decisions about their antenatal care. But the survey responses also highlighted areas where care could be improved. Fourteen per cent of respondents said staff did not do everything they could to help manage pain during labour and birth. Furthermore, a quarter (25%) of respondents felt they did not have the opportunity to ask questions after their baby was born, and only 58% of people surveyed said they were 'always' given the information and explanations needed (compared to 60% in 2023).

Long term conditions and the impact on women

There are many conditions that appear to disproportionately affect women. One such condition is Myalgic Encephalomyelitis (ME), also known as Chronic Fatigue Syndrome (CFS), with women nearly four times more likely to be affected than men. Following a commitment by Sajid Javid in 2022, the Government has developed a cross-party interim delivery plan for improving support for those with ME. The interim plan has a significant focus on education and training for professionals, and a commitment to more research into ME. The creation of the interim plan has been

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[9] https://www.cqc.org.uk/publications/surveys/maternity-survey

repeatedly delayed. Despite this recent focus, a study by researchers at Edinburgh University, reported in the Times, found people with ME “felt invisible and ignored” by the NHS, with many struggling to access support[10]. The report also highlighted the significant barriers to getting a diagnosis and ongoing help, as there is no diagnostic test and no cure.

Medical misogyny and reproductive health

In December 2024, a new report by the Women and Equalities Committee[11] (a Parliamentary Committee) warned that “Women experiencing painful reproductive health conditions such as endometriosis, adenomyosis and heavy menstrual bleeding are frequently finding their symptoms ‘normalised’ and their ‘pain dismissed’ when seeking help.” Their report painted a damning picture of stigma, medical misogyny, poor education, and limited, often painful options for treatment.

These findings were mirrored by the work of academics at the London School of Hygiene and Tropical Medicine, showing almost one in four women have a serious reproductive health issue[12]. The study also highlighted significant racial disparities.

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[10] https://archive.ph/56ero

[11] https://committees.parliament.uk/publications/45909/documents/228040/default/

[12] https://www.theguardian.com/society/2025/apr/10/one-in-four-women-england-reproductive-health-issue-survey

Local picture

The Woman of the North report[13], published in 2024, by Health Equity North makes clear the inequalities faced by women in our region. In short, Women in the North of England live shorter lives, work more hours for less pay, are more likely to be an unpaid carer, and more likely to live in poverty than women in other regions of England. Speaking about the report, Professor Kate Pickett OBE said

"This report unpacks some of the wide-ranging challenges women face across many aspects of their lives, and the impact of these on their health. For women in the North, these challenges are often felt more deeply.

We know that much of the inequality we see affecting women in the North is a direct consequence of poverty, which is completely unacceptable in the 6th largest economy in the world. Cuts to welfare and public health funding, the pandemic and the cost-of-living crisis have hit the most deprived communities and the North hardest."

Women's Health Hubs

Through the Women Living Well Longer programme, Humber and North Yorkshire Integrated Care Board (ICB) has been working to establish women's health hubs. Locally, four priorities have been identified:

1. Reducing health inequalities and improving access
2. Creating sustainable services
3. Putting women's voices at the centre
4. Involving the whole health system.

The hubs will focus on delivering improved support to women around:

1. Access to contraception

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[13] Woman-of-the-North-report.pdf

2. Menopause care
3. Pelvic health

Perinatal Mental Health

The issue of Mother and Baby Units for women experiencing significant mental health issues following giving birth has a difficult history in the city. There were plans from the 1970s to put a mother and baby unit in Clifton Park Hospital, but the hospital was closed in the 1980s[14]. Bootham Park Hospital had a mother and baby unit, though this was not consistently open[15], until the hospital's sudden closure in September 2015[16]. At the time there was concern about the loss of the mother and baby unit. In 2016, York Press ran an article with the headline "York mum with postnatal depression sent 100 miles from home[17]". There is no unit in the Humber and North Yorkshire area. Our closest units for York are in Leeds, Morpeth, Nottinghamshire and Derbyshire. There has been a national call to increase the number of mother and baby units across the UK[18].

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[14] https://archiveshub.jisc.ac.uk/search/archives/21acbffc-3876-3cda-9a0b-a9e4ee1d46c6

[15] https://www.bbc.co.uk/news/uk-england-york-north-yorkshire-17221703

[16] https://www.yorkpress.co.uk/news/13791812.Bootham_Park_Hospital__Anger_and_upset_mount_as_doors_close_today/

[17] https://www.yorkpress.co.uk/news/14234197.york-mum-with-postnatal-depression-sent-100-miles-from-home/

[18] https://maternalmentalhealthalliance.org/campaign/specialist-services/

York stories

Menstrual health

Personal stories: 'Sitting in the toilet to eat' – Beth's story

I had heavy periods from my 11th birthday. I probably went to the doctors about 100 times before I turned 17, and then just overnight I started getting pain every day, not just on my period and I was missing college and missing social events, and 17 is quite a delicate age. So, I remember going to college and sitting in the toilet to eat my lunch because I didn't have any friends. I'm in so much pain I don't know what to do. I went to A&E. I was sent away from A&E a couple of times with just oramorph and expected to take that every day whilst driving and going to college.

Personal stories: 'A familial pattern' - Louise's story

There is a familial pattern. My mum started at a similar early age (10 and I started at 11) and my daughter the same (11). My periods were very regular, often to the day, and very heavy. Mum was really good at sharing her experience, when she first started her period - she thought she was dying as no-one had told her about it.

My experience was horrific. I started wearing a bra in year 5. At school the PE teacher said to us to talk to her, but she wasn't approachable and it would have been obvious what was happening if anyone had talked to her. My period started at school. I just used some paper towel and went home to talk to my mum.

The school lesson about periods happened after my periods had started! I didn’t ever ask for help with my heavy periods, I just got on with it.

When I look back, my mum had a difficult time. She did go to the doctor about PMT and I remember her being slightly mad and my dad with his head in his hands. She was referred to a trial in Leeds for starflower and evening primrose oil. She also had a hysterectomy at 44.

My daughter also has very heavy periods. We had talked about it before they started. She went to the GP when she was 13 or 14 (before this I always sent her to school with a wash bag of supplies, just in case. The GP’s answer was to go on a low dose pill. This did help, but she stopped at 17 as my daughter felt that her personality had changed.

I think they need to do education for boys as well as girls about periods. My daughter once asked her brother and he thought girls/women bled for a month.

Personal stories: ‘It’s my choice’– Tierra’s story

When I was younger I suffered very heavy periods. Mother did too – it was just something women had to deal with. In my 20s, I basically destroyed an office chair passing a clot. I had to hide it from colleagues. When I told the doctor they were good – they said we should do something about this.

Birth control helped, but some doctors brought their own agenda to this saying things like “You have to bleed sometimes.”

I got iron tablets because I was anaemic. Eventually I looked into options – I was refused a hysterectomy at 40 even though I don’t want kids and I have mental health issues: having a child could cause psychosis. I get where they are coming from “you might change your mind.” But I know my own body and mind and it’s my choice.

I started doing my own research into androgen. If there was an androgen imbalance this might cause the issues I have. But when I raised this, no one was interested.

Fertility

Personal stories: ‘Completely let down’ – Mary’s story

I went to the GP earlier this year with symptoms of PCOS (poly cystic ovary syndrome). I was referred quite quickly to York Hospital for scans and tests. The GP confirmed with me that I do have PCOS but wasn’t willing to help with symptoms unless I was actively trying for a baby and told me to come back then.

I put in numerous requests to be seen as, due to insulin resistance, I can’t lose weight naturally. I need to lose weight in order to go through with IVF. The GP got back to me via no-reply text after an eight week wait to say that they will refer me to Tier 3 Weight Management services. But this referral came back with the GP saying I don’t fit any of the criteria that North Yorkshire ICB have set and that they suggest I go to Slimming World instead. But I have already told them this hasn’t worked for me.

After looking into things a bit more, I did a self-assessment to Oviva (an NHS weight management program) but again, my GP came back saying I don’t fit any ICB criteria and do not have the right to choose. I did get back to my GP asking to clarify how I don’t fit ICB criteria as from research, I do and also how I don’t have the right to choose. They have stated I will have another eight week wait for a response with this.

Overall, I feel completely let down by my GP, they gave me a diagnosis and basically said to get on with it by myself and won’t help me lose weight nor will they allow any other service to help either.

I am at a loss which is affecting my mental health as I can’t afford a private endocrinologist and can’t move forward with IVF until I lose weight.

> I have also struggled to get through to a GP. All the responses I’ve received have been either no-reply texts or GP receptionists passing on messages. I haven’t spoken to a GP since I went to an appointment with my symptoms near the start of the year.

Contraception

> *That they fit coils in people without numbing, proper pain relief is absolutely barbaric, horrific, cruel and unnecessary.*

Personal stories: 'Frustrated' – Tiana's story

My GP told me that they were no longer prescribing contraceptives. They said I should go to a pharmacy. I did that, but at the pharmacy they told me they weren't yet able to prescribe contraceptives. I've got mobility issues so I struggle to get to any pharmacies apart from the ones most local to me. I need to find a solution. I'm really frustrated that my GP stopped this service without making sure my pharmacy was able to prescribe contraceptives.

Personal stories: 'They all said no' – Penny's story

My GP gave me a prescription for contraceptives. I was then told I didn't need to renew the prescription, but could get the medication via my pharmacy. I phoned three pharmacies who all said no, they needed a GP prescription.

Maternity

I had an ectopic pregnancy in July 2021 and ended up in York Hospital. My husband wasn't allowed to be with me and I was in a women's ward with a wide variety of different people. It was an awful experience and I didn't want to go back to that hospital ever again. However, I have since had two children there and they have been very good. I had very good birth experiences.

Personal stories: 'Second opinion' - Rachel's story

I was on methadone when I had my first son, Dylan, two years ago. I was at another appointment at York Hospital when labour started. I was put in a room on the ward and left there. I was in a lot of pain and I'd always planned to have an epidural. But by the time the staff came back to me it was too late for pain relief and my son was born just 18 minutes later.

Every day on the ward they told me I could go home, but that wasn't true as I had to stay in for five days while they monitored Dylan for withdrawal symptoms. He was being monitored regularly and there were no issues.

On the fifth day I went outside for a cigarette, which the nurses suggested and said was fine. While I was outside, the nurses took Dylan for an assessment without telling me. They asked a different doctor who said that he was having issues withdrawing so they were referring him to a specialist team.

My partner and mum were both at the hospital, and they said Dylan was no different. I asked for a second opinion and that second doctor said he was fine and we were all OK to go home.

While I was in hospital I felt that they started giving me my methadone later and later. It puts me off having another baby there. But one good thing was my midwife who was excellent.

Personal stories: 'Too complex' – Fay's story

I have a number of neurological and other issues. When I became pregnant my doctors all discharged me as they said they wouldn't be able to tell which symptoms were to do with my pregnancy and which to do with my long term health conditions. I was very disappointed. I have now chosen to go to James Cook Hospital as they seem a lot better. The different departments seem to talk to each other and the care is much better even though I have further to travel.

Personal stories: 'Indigestion' – Scarlett's story

My experience of pregnancy and giving birth…. I want to start by saying that there are some wonderful midwives. But one or two were not good. I was supported by a newly qualified midwife. I felt that they didn't really know enough to be working on their own. She didn't know the answer to almost all the questions I asked. She was lovely, I'm not criticizing her, but she needed more support at this stage in her career. I had significant pains. I asked about them but was told it was indigestion. After giving birth, the pain continued at which point they diagnosed me with gallstones and removed my gallbladder. My baby was induced. I was in intense pain and asked for medication but I was told I was not in labour and it would be another 12 - 24 hours so there was nothing that could be done. My husband was told to go home. Four hours later my baby was born as the pains had been labour. I didn't get any pain medication. My husband got back just in time to see our daughter born.

Personal stories: 'A living nightmare' – Willow's story

I would like to complain about maternity services which I can only describe as a living nightmare. Our lovely granddaughter Willow had her baby three weeks ago which should have been the best time of her and her partner's lives but sadly wasn't. Willow had an epidural which went drastically wrong. After days of going backwards and forwards [to maternity] her husband woke to her having seizures (she'd never had one before). She was rushed to hospital where I can only describe the next four days as living hell. No neurologist on site? No scan for days as it was a Bank Holiday? Couldn't have her newborn with her unless family slept at her bedside? Willow ended up on a renal ward as [there was] no bed availability on the correct ward where she was finally diagnosed with a blood clot on her brain which had caused the seizures. ([it was a] problem with the epidural [that] caused this). Even though Willow is now home on heavy duty medication she needs 24 hour supervision. This is not what anyone should endure; our NHS should have the correct staff available at all times. Emergency health problems DO NOT only occur during normal working hours. Why is this happening?

Personal stories: 'I wish they'd listened' – Nikki's story

I have back pain caused by arthritis and a slipped disc. There are some great people at the hospital, who supported me when I was expecting. But not everyone was so great. When I asked one staff member if there was anything that could help with the pain the response I got was "what do you want me to do about it?" I had a planned caesarian. The anesthetist was brilliant and coached me throughout. I was having a spinal block and I made sure that I had told everyone about my back pain. I even brought my medical notes with me. Despite telling everyone, the person who did my spinal block asked "do you have any back problems?" I gave them my notes and everything was fine. But I wish they'd listened to me in the first place rather than asking again. I had some problems breast feeding as my baby wouldn't latch on. When I asked a midwife for help they basically shut me down, saying "what would you do if we weren't here?" and then told me to calm down. I was very upset by this. Thankfully a different midwife came later. She was very understanding, supportive and helpful.

Personal stories: 'Lucky I came in' – Maggie's story

When I had my oldest child, the pregnancy significantly affected my thyroid. After giving birth, my health really struggled. I had awful headaches and more. I went to the GP twice. Both times they were phone appointments with a male GP and both said it was just the situation of being a new mum. I knew that wasn't the case and I was feeling awful. I tried again and spoke to a female GP who recognised what was wrong and referred me to York Hospital. The consultant said that it was lucky that I came in then as I had critical levels of hormones and needed immediate treatment. Other than that, the GP practice has always been excellent.

Personal stories: 'Amazing until....' – Tamsin's story

I had my second daughter [a few] months ago in York Hospital. The experience was good until I went to the postnatal ward. That service needs significant improvement - there was a lack of any support. I had an allocated midwife, but I had to go to the nurses' station as no-one would come if they were needed. We forgot to take cotton wool with us so we asked for some. We were told that, even though the nurses had some, we needed to go and buy it. I was given no information about breast feeding until I was leaving to go home. It also didn't feel like the proper checks were being done and it took six hours longer than needed for us to be discharged. I've heard similar experiences from other mums. It's a shame as the experience on the labour ward and from the community teams was amazing.

Personal stories: 'So impersonal' – Maddie's story

The Badger Notes app is now being used in pregnancy. But the system is so impersonal and black and white - if your pregnancy situation is non-typical it is really stressful to try and use.

I've had two miscarriages in the past year. I found out quite late that I was pregnant. I thought my exhaustion and sickness was down to stress. When I reported this pregnancy in late I had to keep chasing because I knew I hadn't had a booking appointment and so wouldn't be offered a 12 week scan - the cut off for doing that is at 14 weeks. They did squeeze me in but I found I'd already lost the baby by the time I went for that 12 week scan late at 14 weeks.

So I left it on my phone and just didn't ever open it again. I didn't want to log in and face a screen that might be telling me what stage of development the foetus was at for that particular week. There was no advice, information or explanation of what to do next with that app or if information was updated to offer different advice or stop that tracker continuing when you miscarry. I reported another pregnancy using the link to the Badger Notes app again in February when I got pregnant but used a different email so I wouldn't have to see any of the old information in case it was still there. I then miscarried again quite early. It was before I'd heard from a midwife, so I never had anything more to do with the app that time. The form I had to complete was also not helpful if you've experienced miscarriage. From what I remember it asked if it was your first pregnancy but the answer was Y/N with no option to explain that you hadn't carried to term. I suspect this would be useful information for a clinician as the risk factors are different if you've had children previously.

I've just found out I'm pregnant again, but felt forced to log in to the app as I have run out of alternative email addresses to use. There's no way for me to report a new pregnancy if I'm an existing user. On the page I had to open to try and update my case notes - I've got a 'sorry your baby has died' message.

I popped into the GP practice earlier to get the link and spoke to the receptionist. I explained that I had experienced a miscarriage but now needed to report in a new pregnancy. I did this in case they needed to give me something different. However, it seems to just be a standard link that they give out, they didn't have anything else.

I spent a while on hold this afternoon trying to speak to someone to see if I can report in a pregnancy in a different way, but they couldn't give me a number to contact the midwives directly, or any other alternative. The receptionist has passed the issue on to a GP so I'm waiting on a call back. I'm certain I won't be the only woman who has experienced miscarriages and had these issues with the app. I'm pretty resilient, but did end up crying on the phone to the GP practice when I tried to explain the situation. It feels needlessly distressing and impersonal. Eventually I found out you can contact the midwives direct, the GP practice passed on a number.

Personal stories: 'Over the threshold' - Lara's story

I went for my 40 week scan as I was pregnant. I had some other checks and they noted that my BMI had increased and that I would need to talk to a consultant as it was now over the threshold. I suggested it could be because I was heavily pregnant. The consultant said they had to ask as my BMI was over the threshold.

Personal stories: 'I nearly died' - Quinn's story

Women are called the fairer sex, but when it comes to pain, we are the stronger ones. I nearly died when I was giving birth. They had asked me before about pain relief and I said I wanted a tiered approach. No matter what happened, they stuck to this. So, even when I was clearly dying, they didn't offer me anything different and just waited. I was tachycardic and then brachycardic before they did anything. They were concerned about my son, who hadn't been born, but didn't realise that his vitals were dropping because mine were. In the end they had to do a crash C-section. The pain was horrendous.

I did a subject access request for my notes and it was full of lies and missing information. They didn't include that I had asked for assistance for a bath (I was covered in blood and viscera after the birth and C-section). They said no one could help, so I'd have to do it myself. I managed, but it took four hours to get a shower. I felt abandoned after I'd given birth. It is as if the medical professionals feel that birth should be painful, so women should just get on with it. When I was having my caesarean they were rushing. So they were only just doing the pin test to see if I was still aware as the surgeon was about to make a cut. I could feel the pin and had to shout to stop them. It was dehumanising.

Personal stories: 'Amazing until….' – Sadie's story

I chose to have an elective caesarean. My pregnancy history was complicated and I was feeling anxious. This felt like the best option for us.

I was in all day waiting and they called me to theatre. A midwife got me ready to go and they cancelled after we'd got to the theatre. I spent 20 minutes outside the theatre in a gown expecting to be called in at any moment (this was late afternoon. I'd been in hospital since 7am and nil by mouth since 10pm the previous day).

If they'd told me it had been cancelled on the ward it wouldn't have been so bad. But I'd asked for an elective because I was so anxious. This obviously did not help a bit! The communication just felt so poor when someone must have changed their mind in a 20-30 minute window and we had an awful, anxious wait.

The wait for the next available c-section slot was long too, from the cancelled one to the next available slot was nine days. So quite a tense week or so of waiting for us.

Midwifery and postnatal care

> *I have no idea who I can speak to. The second appointment [was] on video. The call lasted five minutes maximum*

Personal stories: ‘Concern identified but ignored’ – Zoe’s story

When my baby was born, the midwife said he had a mild tongue tie and this should be checked at the six week check. That was with a GP and I mentioned the concern, but the GP said it was fine and didn't need anything more.

However, I realised that it wasn't right and went private to get advice. They said that it was a tongue tie which was affecting my son's eating and his neck. They said he needs a minor operation. I went back to the GP, but they said that York Hospital wouldn't do it as my son was now 11 weeks old. They were going to refer us to Leeds but it would take time. My in-laws offered to pay so we're going private.

It is really frustrating and shows that the GPs need a lot more training. This is something that should have been picked up and dealt with, especially after the mid wife had mentioned it, but it seems that GPs don't know what to look for.

Personal stories: ‘Failing to thrive’ – Chrissie’s story

I had lots of problems just after my son was born and for the first years of his life (he is now 18 months old). I had problems breast feeding and no one was helpful either on the post-partum ward or when I was home. They didn't seem to have the training that meant they could help. The baby had his new born tests but they didn't identify anything. However, the baby wasn't feeding and was losing weight and I was told he was experiencing a 'failure to thrive'.

We were so worried that we chose to use our savings to go private. The person we saw identified he was tongue tied and arranged an operation and treatment, including things we had to do at home, which made all the difference.

I know the staff at the hospital and was disappointed that they hadn't spotted the issue after he was born. They said that it can be difficult to identify a baby is tongue tied, but the staff should have had the training to identify that that was the problem.

There really needs to be more and better training for maternity staff about a child being tongue tied, but also about what to look for, including that, if a child isn't feeding. I was really keen to pursue breast feeding and I was able to later, but a lot of new mothers I spoke to just gave up. But better support would make all the difference. I also needed support from the perinatal mental health team. When I saw them they were really helpful, but I had to wait for eight months for psychological support and was only able to have support until my son was 12 months old, which limited the help I got. It would be better if you could get support earlier.

Perinatal Mental Health

> *Birth trauma is very real but it feels there is an underlying culture that 'we have all been through it', 'women have been doing this for years'. This is completely true but that should not diminish the fact that each person's experience is very personal and unique to them.*

Personal stories: 'Untethered' – Sophie's story

I'm neurodivergent and have experienced poor mental health in the past. I was also still grieving the death of my mother when I found out I was pregnant. So I was under the perinatal mental health team throughout my pregnancy.

I had a planned caesarean in the summer, at the same time as a major stomach operation. This gave me a huge scar from one side of my pelvis to the other. They removed 6lb of old skin that would not have been able to heal after my caesarean.

I was in York hospital for six days. I was given opioids and tramadol in hospital to keep me comfortable. I was discharged with tramadol but without opioids as I was breastfeeding.

When I got home, I couldn't switch off. I was awake without sleep for three days. I slipped into psychosis on the evening of my third sleepless night. I wasn't eating or sleeping. I locked myself in the bathroom, and then lost control of my body and couldn't reopen the door. So I had no access to medication. The Crisis Team initially came and left because I was locked in the bathroom. They came back once the door was opened.

The Crisis Team gave me diazepam to calm me down. It didn't work. I know now that diazepam is known to react badly with tramadol. When it didn't work they gave me more. I reacted really badly to the second dose – I've never done drugs but when people talk about "being off your head" or "being high", well, that's what happened to me with dose two of diazepam. I completely lost it. I was wild. I hit and bit my husband. I'm not a violent person, but I simply wasn't myself. I firmly believe I had a paradoxical reaction to the diazepam. At this point, I was sectioned.

I was taken to Foss Park and given haloperidol. This finally let me sleep. I woke up in Ebor ward the next day after 13 hours of sleep. I had very little with me – I woke up virtually naked wrapped in a dress and a blanket. I knew I'd had a baby but I didn't even have a picture of her with me. People kept asking me what she looked like and I genuinely couldn't tell them which was distressing. I also didn't have a breast pump. My husband brought some of my things, but they were locked in the office and for the first couple of days I wasn't given them. I did ask, but there were lots of delays.

I started to develop mastitis – my milk was getting blocked. I raised it with staff, and was told "we don't normally handle postpartum psychosis; it's usually done in the community." A fellow patient, seeing how distressing and uncomfortable this was, took me into my room and cried out "feed me, feed me, I'm a baby, wah wah" to help me express my milk by hand massage. It was surreal, but it actually really helped, and I am so grateful to her.

I saw the perinatal mental health doctor, who talked to me about medications and about changing my bandages. But no one talked to me about the situation I was in – having just had a baby and being separated from her, my older child and my husband. It was so hard being separated from everyone. I finally got my photos of my baby and family on my third day on the ward. At a point where I desperately needed anchoring I felt untethered without these vital possessions.

On the fourth day after admission I finally saw my family again, but only briefly, before I was transferred out of area. We don't have a mother and baby unit in York and Leeds, an eight-bed unit, was already full. So late in the evening of that fourth day I was transferred by ambulance to the six-bed unit in Morpeth, 110 miles away from my family. I asked for an Independent Mental Health Advocate (IMHA) but there wasn't time.

In Foss Park staff were nice and well-meaning but there weren't processes and procedures or care pathways for breastfeeding mums. By the time I was able to be with my baby again my milk had already started drying up. I was still unwell. I was still struggling with holding because of my scar. This may all have happened anyway but I believe it was because I spent most of a week without my baby and without breastfeeding help.

The care at Morpeth was great, but it is such a long way away. My husband had to take a week's unpaid leave to be with me. He also spent over £700 on petrol, hotels and meals which all had to go on a credit card. They involved him in conversations about my care, but he felt like there weren't really any good options for hospitalised women with post-partum psychosis.

The reality is there are simply not enough mother and baby units. I should have been in Bootham, not transported miles away. Morpeth was outstanding, a purpose-built unit with great staff and facilities. York could have some really great support options around a women's wellbeing hub if something like it was built here.

My husband hasn't been well – he's been through this ordeal with me and is exhausted and traumatised. He was referred for a carer's assessment which happened in July but we haven't had any practical help yet. There's still a lot I can't do which has made all this even harder. I worry for him carrying so much.

Personal stories: ‘Lost in the system’ – Lydia’s story

I was suffering from post-natal depression and my GP had referred me to the Community Mental Health Team (CMHT). I was told to expect them to make contact within two weeks. Eight months later my GP called me to see how I was getting on with CMHT but I hadn't heard from them. I later had a telephone consultation and they said I needed to be referred to IAPT (Improving Access to Psychological Therapies). I then didn't hear from IAPT and assumed I had just got lost in the system. Fourteen months later out of the blue I received a call from them asking if I had received any care.

Menopause and perimenopause

> *I've had to pay a private GP for some worthwhile menopause advice.*

Personal stories: 'Full ovarian failure' – Gemma's story

I never had a problem with periods, but I did start when I was 11. I had no idea what was going on as no-one had ever told me about them.

Since I had my son, Archie, aged 19, I've had anxiety and I've often felt flustered and uncomfortable. I've never known why or what triggered these feelings.

When I was 31 my periods stopped. I went to the GP about it and they asked if I could be pregnant. I knew I wasn't but they didn't listen and did nothing.

Six months later, still no periods, a GP sent me for a blood test. This showed 'full ovarian failure'. A receptionist had to tell me this and she apologised for the brutal medical language. The same GP asked about my symptoms, but they said I was too young for HRT as it would increase my risks of breast cancer. So they prescribed me the combined pill.

I took that for two years and then went for a review to a pharmacist. The pharmacist told me I should have had two blood tests originally to check my hormone levels. She also said that I should be on HRT as the rules had changed so younger people were OK to take it.

I was still experiencing a lot of symptoms. But to be prescribed HRT, the pharmacist said I'd need to stop taking the pill for four weeks. I'd then have another blood test to check hormone levels before starting on HRT. This was the worst month of my life. The pill had helped with my symptoms. I didn't have that, and it was August and there were two very hot spells that month. I was having hot flushes all day every day.

When I had the blood test it showed that my hormone levels were even lower. I was prescribed the HRT patch and progesterone. The patches were supposed to be waterproof and sweatproof but they weren't.

The new treatment did help. But by this time I didn't know what normal was. Maybe I've been perimenopausal since my early 20s.

For the progesterone, the doctors tried to encourage me to have a coil. But I was adamant that's not what I want. Eventually I found out that I could have it as tablets daily. I also changed to have oestrogen gel twice, once in the morning and once at night.

At this point I was still bleeding and didn't know why. From the day that I started the new treatment I bled for 28 days continually and then every other week for a week for a year.

I let my GP know about this and they referred me to an endocrinologist and a gynaecologist. The subsequent scans and tests ruled out a lot but never explained why this was happening.

It is only in the last six to eight months that the bleeding has stopped.

I still have symptoms, but it is much better. However if I forget to use the gel, my symptoms increase a few days later.

When I look back, my symptoms were awful. The intense hot flushes I had felt almost like panic attacks. I don't know how I coped in the hot August, I just remember having a glass full of ice in my hand at all times and a neck fan which was essential. My head was full of cotton wool and I constantly panicked that I would forget important information. I struggled to sleep and always felt lost.

No one has talked to me about what happens in the future. For now I'm on both progesterone and the HRT gel and these are reviewed every six months. I've now seen the menopause specialist at the GP. This has been good and helpful, but overall I feel that GPs don't understand. I don't think I can be the only person who has had early menopause, but that's how it feels.

I think there needs to be more information and discussion about perimenopause. I also think different language to talk about things would help. Full ovarian failure is a very brutal thing to hear.

A lot of my symptoms were put down to something else. If I hadn't had that medication review with a pharmacist I might still be on the combined pill and struggling. Whenever I have a medication review with a male doctor, they ask why I am taking the progeterone and oestrogen. I guess it is because of my age, but there is no other reason than menopause to take the medication so it is a strange question. Female doctors never ask.

One thing I'd like to see change is that women are listened to and all their symptoms taken seriously. You can be in perimenopause or menopause and still have anxiety or depression.

Personal stories: 'No holistic care' - Angie's story

At the same time [as trying to get an ADHD diagnosis] I was experiencing the peri-menopause and my symptoms got a lot worse. I could not cope with the combination.

I went to the GP and was put on HRT with no checks at all. I was told if the HRT didn't work, they'd review it in a year.

The first HRT didn't work and within two months I asked for a review. They said no. They also said they wouldn't refer me to the menopause clinic as it was closing and they weren't taking any new referrals. I couldn't find any information about that.

I rang the menopause clinic to ask how to get a referral when a GP was refusing and they got me an appointment for the next week. I saw someone in October, had bloods done and they talked about increasing the HRT dose and then reviewing in December.

In January I went back to the menopause clinic, but I didn't see the same person. Instead, I saw a GP from [person's original GP practice]. I had monitored my symptoms via an app and took the report, but they refused to look at it.

They said I needed a Mirena Coil, but I don't want one. The previous person I saw had mentioned HRT with more testosterone, which I wanted to try. The GP person said that they would refer me for a coil and for testosterone-based HRT.

In December I had very bad diarrhoea and bad abdominal pain for seven weeks. I eventually went to the GP. I was sent to [GP surgery] and saw a Primary Care Practitioner who was very good. They listened did some tests and followed up. They sent me for a CT scan and referred me to the consultant. I spoke to the consultant on the phone who was lovely.

I had also gone back to the GP to say I didn't want a Mirena Coil. They also referred me for an ultrasound which found I had fibroids. As a result, the GP said they wanted gynaecology advice and made an urgent referral. However, urgent referrals at York Hospital are taking a minimum of five to six weeks.

I then had to go back to the GP as I had bad abdominal pain and bleeding. They arranged for the consultant to ring me. When they did, they had no record of the ultrasound. There is no holistic care between GP and hospital.

The GP doesn't understand the issues I am facing. Doesn't recognise I had an NHS ADHD diagnosis and the impact of menopause on ADHD symptoms.

I am thinking about changing GP, but don't want to do anything until the other health issues are sorted out.

Personal stories: 'Almost written myself off' – Jodie's story

I hadn't heard of the peri menopause until a social group I'm part of were talking about menopause. One person lent me a book about it which was really useful.

So then I talked to my mum about her experiences. I found out that she started peri menopause at a similar age to me which was also useful to know.

I was first aware of symptoms when I was around 39 or 40. I'd just got a new job at a call centre. It was more restrictive about what I could do when, including going to the toilet, as I was answering calls.

Not long after starting work there I had a series of urinary tract infections (UTIs) every few months - I later realised this was an early sign of the peri menopause.

A year later I started with night sweats. I woke every morning drenched and feeling awful.

I went to my GP but they said at 42 I was too young for menopause. One GP suggested taking meno-herbs. I was sceptical but I tried them and after six months the night sweats were gone.

When I went to Boots to get more meno-herbs the pharmacist explained I could only take them for six months. So I stopped and despite my worries, the night sweats didn't return.

Six months later I had more symptoms including feeling exhausted. I often had to sleep during the day at the weekend. My job was going well, but I was struggling to be awake and yawning a lot. I also had aches and pains all over and felt awful.

I went back to the GP and luckily this time I saw a doctor I'd known when he was training and I worked with him in a health role. He was very empathetic and listened as I listed out my 19 different symptoms. He ordered a blood test and after getting the results referred me to a female doctor. She said the blood tests didn't really tell her anything, but she wanted to focus on my symptoms which indicated menopause. So she talked to me about starting HRT. I'd done some research and I knew the gel was getting better reviews than patches so I asked for that.

This doctor was newly qualified, clued up and more willing to listen to me. I was grateful, but also very frustrated that it took two years of symptoms and feeling awful to get taken seriously and have a GP actually listen to me.

During those two years my self-esteem fell significantly. I gained weight as I didn't feel able to exercise because I felt so awful and exhausted. In all honesty I had almost written myself off, feeling about 100 years old, with only enough energy to go to work and see family.

I felt unattractive, my moods were all over the place. I was starting to struggle with losing words which was very difficult given that my job involved talking all day. My calls got longer as I had to find work rounds when I couldn't recall a word. This led to me feeling overwhelmed and panicky. I even started to wonder if I could only work part time from now on. I just felt utterly miserable.

I only got through those two years as other women recommended things that helped. This included a herbal treatment that helped with my UTIs.

After taking HRT, I feel like I have got my life ahead of me again. My memory is better, I have more energy and I simply feel a lot better. I have started running again and I've lost weight.

On talking with my new GP, I raised my UTIs, and the GP suggested a pessary which has helped.

The one issue with the HRT is that every time I need to reorder, usually every three months, I have to have a blood pressure check and be weighed. I don't know why this is, no one has ever explained. For my pill prescription I have a blood pressure check every year so I wonder why it isn't the same for HRT. For HRT this means a quarterly trip to the GP to get my blood pressure and weight done which isn't always convenient.

I would like to see changes because no-one else should have to go through the years of misery I had. I want GPs to improve and listen to patients. They need to take time to listen to people's symptoms and not simply dismiss them as being too young when there is clearly something wrong. The symptoms are key, not someone's age.

Personal stories: 'Dismissed before private care' – Daria's story

I had a variety of symptoms but wasn't sure what it could be. My main feeling was simply that I didn't feel myself. When I went to the GP, they asked me what I thought it was. I said I didn't know and that's why I was here. I felt dismissed by the GP I saw because of my age as they didn't think it could be perimenopause.

I didn’t feel listened too. So I went to Nuffield privately. Here, they did listen. I was told by the female medical professional that I saw that I didn’t have to put up with my symptoms.

I was waking up with soaking sheets. I’d even taken a photo to share to explain what was happening. I also had anxiety and depression.

I was referred to the gynaecology team at York Hospital and I am now on HRT.

Personal stories: ‘I burst into tears’ – Mel’s story

My symptoms included brain fog. One day while driving I couldn’t remember which side of the road I should be on. When I went to my GP, they wanted to put me on antidepressants. But I’d only just managed to get myself off those and I didn’t want to start again. One of the reasons my GP thought it was depression was that when they told me I could only talk about one symptom, I burst into tears.

I went home and thought I’ll just have to deal with everything on my own. And for the next five years that’s what I did. I used diet and exercise to help with my symptoms.

Eventually I got referred to the menopause specialist GP at the women’s centre. I was tearful and got talked into taking some anti-depressants. But my joints inflamed and so I stopped. Finally the GP suggested HRT. These have helped but by this time I hadn’t had a period for 18 months so I don’t know if was just time or the HRT that helped.

I would like to see GPs offering more options to talk to a GP about physical and mental health and have more mental health specialists in primary care. I also feel that women should see women GPs as you need to talk to someone who understands the issues you are facing when they are specific to women. You should always be able to ask to see a woman GP.

Personal stories: 'Misinformed on three occasions' – Grace's story

I have found it difficult to see a GP and particularly hard to get good advice on menopause. I have spoken to three different people and was misinformed on three occasions. Thankfully I had done some research in advance so I knew what I needed. But it is a gamble to get a good GP now.

Personal stories: 'Too young' – Caroline's story

I had an issue and rang the GP practice in tears. The receptionist just said I had to fill out a form. I feel that I am peri-menopausal as I have the right symptoms. I have tried to contact my GP practice five times and the only response I have had is that I am too young. Another time I was offered depression medication - this without being seen or listened to. Instead I asked my breast nurse (who I know due to a previous cancer diagnosis). She arranged a blood test which showed I am in fact peri-menopausal. But I still can't get any feedback from my GP...

Personal stories: ‘It can’t be menopause’ – Jude’s story

I have been back and forth to my GP for three years. My periods have been out of sync and I’ve had other symptoms. I initially waited for six months and tracked my symptoms on an app.

When I got to see a doctor, they said I was too young for the peri-menopause (I was 38) but they did say they would do blood and hormone tests. As part of the test results, they discovered I am coeliac (as I mentioned being tired.) So after that they put all my other symptoms down to that. But that is not the case.

They have referred me for an endoscopy, then to see the dietitian (18 months wait for an appointment) and to see the consultant (six month wait after the endoscopy). I have had a number of letters for my endoscopy but each time I then get a letter cancelling it.

The treatment for coeliac disease hasn’t helped any of my other symptoms. They are not to do with this.

So I went back to my GP with the same symptoms, this took nine – 12 months. It was similar to the first appointment (with a different person) where they did tests and these came back normal, so nothing else happened. But my symptoms are still there and particularly brain fog, periods all over the place, low libido, fatigue… As I didn’t mention hot flushes they said it can’t be menopause.

I contacted the GP again for an appointment and was given an appointment on [day] by text. I rang to change the appointment as I was away. But every time I rang I got a message saying ‘we are experiencing a high level of calls, ring back later’. I did, but the message was the same. I did get through, initially they couldn’t find the appointment, but then cancelled it. But they didn’t seem to then rearrange it, which is what I wanted. I kept calling and was told a clinician will call you on a particular day in the morning. But that doesn’t work for me. I have three children and could be busy with school drop off. I tried to call back, but couldn't get through and you can't reply to a text message.

Once I spoke to someone they did the same tests again and they came back normal. But this time they did refer me to the menopause clinic. I am going soon.

Personal stories: 'A long wait to change HRT' – Harlow's story

I spoke to the doctor a couple of months ago about reviewing the HRT I am taking and possibly trying something new as I am still struggling. I had a blood test and had to then make another appointment, waiting eight weeks, to discuss changing my HRT. That is a long time.

Now I am on HRT I have to get bloods done every three months and have to arrange an appointment which isn't easy. I am losing faith and don't believe I will ever see anyone.

Personal stories: 'Management of conditions is inconsistent' – Tess's story

I have a number of health conditions including a heart problem, Crohn's disease, arthritis, a stoma and menopause.

If I mention palpitations related to menopause as a symptom, the online form immediately tells me to ring NHS 111. I have a heart problem, so I know what is urgent and what isn't.

Before Covid the GP was very good at helping me manage my conditions, but now it is inconsistent. I have to continually repeat myself to different doctors and I am worried I will end up in hospital as things are no longer well managed. Now they send me a questionnaire about my health, rather than talk to me. It is just a tick box. It doesn't feel like they are interested.

My consultants send letters to my GP, but the GPs don't do anything about them. The consultant said I need HRT medication on repeat prescription but I don't get this. I have to order it and can only order a week in advance. Then I have to try and find a chemist that is stocking it due to the shortages. Boots website is very good at telling you what is available where.

The GPs never look at my notes, so I have to spend most of the appointment telling them things they should know. I often have to book double appointments. Thankfully I usually can do that.

If I want an appointment with a nurse, I can go into the practice to book that. But if I want to see a GP, I have to fill out a form. If I try to book an appointment in the GP practice, they just tell me to go to the practice computer and fill out a form. The forms are not helpful. My issues don't fit. It feels like they don't want people with complex issues.

I have had a stoma for 17 years and now they are asking me if I need all the things associated. Yes I do. I know what I need.

If I ever go to A&E, they just think I am going for painkillers. If I think I need to be admitted to hospital, I talk to my specialist nurses and try and avoid going via A&E

Personal stories: 'Telephone appointment not always appropriate' – Isabella's story

[My GP is] OK and when you see someone it has been good and they seem on the ball. They are good with vaccines. However, you can only get a telephone appointment, which isn't always appropriate especially when you want to talk about the menopause.

The online form is no help for menopause. You can tick lots of symptoms but there is no option that says menopause. Then if things aren't urgent, the option is a phone appointment in six weeks.

They need to tailor the form and have a menopause option from the beginning.

Personal stories: 'Despite our family history' - Rebecca's story

My sister is in the peri-menopause. She has no medication as the GPs say she is too young. She was given anti-depressants despite having a blood test and it showing peri-menopause and our family having a history of early menopause. She is still fighting for HRT after two or three years.

Cancer screenings and care

Personal stories: ‘Made to feel vulnerable’ – Rosie’s story

I had a smear test done by a nurse who made me feel incredibly uncomfortable, silly and vulnerable. There was no consideration for dignity (being asked to get ready without explaining what get ready means, not closing the curtains around the bed or providing anything to cover myself with as is usual practice).

Personal stories: ‘Wonderful nurse’ – Donna’s story

I went for a cervical smear. The nurse was wonderful. She put me at my ease and made a procedure which could be embarrassing and painful, very straightforward and easy. I cannot praise her highly enough. She is exceptional.

Personal stories: ‘It’s not ‘routine’ for me’ – Fi’s story

I am autistic and need time to process. I find accessing any healthcare distressing. It would be better if I had a relationship with someone and if there was some acknowledgement that this is a procedure [cervical smear] that causes distress.

Personal stories: ‘Excellent’ – Ava‘s story

I am a wheelchair user and went to the Magnolia Centre for a mammogram. They were excellent and very helpful.

Personal stories: ‘Impossible’ – Hannah’s story

I work at York hospital and I have really struggled to book a smear test at my GP. I can only book online two weeks in advance but my work pattern means I can't book at that short notice. I need to book it in at least a month in advance. That means I can then change my shifts to make sure I can attend. But this isn't possible. So I’ve missed the date when I should have gone. In the current circumstances I just can't see a way to get it done. I raised a concern with my GP but they said that is the process. There should be another way.

Personal stories: ‘Superb’ – Leonie‘s story

I found a lump in my breast during lockdown. I rang the GP, was first in the queue and had an appointment within two hours. When I got home, I had a message with an appointment at the hospital within two weeks. I was diagnosed at that appointment, had a biopsy and a week later they confirmed the results. Two weeks after that I had surgery and then chemotherapy every week for 14 weeks. Everyone was superb, the nurses were kind, supportive and really great.

Personal stories: ‘Waits too long, care is excellent – Lila‘s story

I have recently been diagnosed with breast cancer. I think that the waits during the diagnosis, for additional scans, were too long for me, but the support and treatment from the Magnolia Centre has been excellent. They are clear, do what they say they will and follow up.

Personal stories: ‘I froze’ - Gabriella‘s story

I had a cervical smear which they wanted to investigate further. I had a colposcopy and had some cells removed. I find anything gynaecological triggering as I had a traumatic birth with both my children. An ex-nurse friend went with me to the appointments. Six months later I had to go for another smear at the sexual health clinic. The nurse invited me into a room and there was a male healthcare professional there. I froze. I asked why he was there and they said the usual person was ill so he was going to do the smear. I said no and dashed out as I couldn’t cope. I complained to PALS and they apologised and said it shouldn’t have happened and I should have been warned it was a man. The nurse also apologised and said that she would do my smear from then on.

Personal stories: ‘Kind and empathetic’ - Dinah‘s story

I has a very positive experience with a smear. They asked for consent at every step. My wife was there as I have a hospital phobia. The staff were all women and eased me through it. They were kind and empathetic at every stage.

Gynaecology

> *I was on a waiting list for gynaecology and my (postponed) appointment was cancelled with two days' notice no reason why and I still have symptoms. Nobody seems at all interested.*

Personal stories: 'They know their stuff' – Barbara's story

> I was eventually referred to gynaecology by my GP practice. The service at York Hospital is very good. They are always on time, they know their stuff and couldn't be more helpful. It is a very good service.

Personal stories: 'All lovely' – Georgia's story

> I came in as an emergency and was referred to gynaecology. The staff there were brilliant. I was seen promptly and they were all lovely and provided excellent care.

Personal stories: 'Warm, friendly, efficient and kind' – Ruth's story

> I had a good experience of planned care with the gynaecology department. The appointment booking was brilliant - I kept having to rearrange things but the hospital accepted this and offered me alternative dates. My care was excellent, the staff were all lovely - warm, friendly, efficient and kind.

Personal stories: ‘My partner could have died’ – Rob’s story

My partner came in for a standard procedure yesterday. She had a local anaesthetic to have a centimetre of her cervix removed as a day patient. They took a bigger area, but said she was OK to go home later the same day even though she was still bleeding. They said the wound had been cauterised so it was fine to go home. But an hour later she was bleeding extremely heavily at home and we had to bring her back to A&E.

It took them three hours to stop the bleeding and in A&E the doctors didn't know that the procedure had happened - either it wasn't on my partner’s notes or they couldn't access the notes. I had to explain what had happened.

Yesterday the medical team accepted that the procedure had led to the bleed and my partner could have died. But today they are just saying it can happen and seem to be covering up what actually happened. It was a horrific experience for everyone, including my partner’s children who thought their mum was going to die.

Endometriosis

Personal stories: 'Felt pressured' – Kate's story

I had a bad experience with the gynaecologist. They ignored that I needed support. I was diagnosed with endometriosis outside of York but ignored in York. I felt I wasn't listened to by the doctor. I had to tell them five times that I was on my period and felt pressured into participating in a physical exam

Personal stories: 'Even the GP was frustrated' – Natasha's story

I saw a GP about some symptoms. They were good and said that they thought it was endometriosis. But even with that it took me three years to get diagnosed. The GP referred me to gynaecology, but they refused the referral and said to see the MSK team. They did diagnose osteitis, so it was useful to see them. They then sent me to a physio who misdiagnosed me with sacrioliitis and gave me exercises for that as well as offering two physio sessions and a referral to a gym. I was referred back to MSK again who referred me back to gynaecology to get an endometriosis diagnosis. Even the GP was frustrated with all this. It seems such a waste of time and money and incredibly inefficient. That said, it took my sister seven years to be diagnosed with endometriosis.

Personal stories: ‘Shaking due to stress’ – Ellie‘s story

I have endometriosis and was trying to find a birth control that would work, but I have vaginismus so it is difficult and I couldn’t have the pill. The only thing they could suggest was the coil. I suggested I would need to go to the hospital to have it fitted, but the GP practice said they could do it. I went to the appointment with my carer and they spotted my stomach muscles shaking due to the stress. It got so bad, my carer had to tell them to stop. They said they could try again another time, but for me to take paracetamol first. It was awful, they never mentioned consent. When I got to the hospital, the nurse asked me about consent at every step.

Long term conditions

Most GPs do not seem to understand or care about illnesses such as ME and fibromyalgia.

Personal stories: 'I'm frightened' – Immy's story

I was diagnosed with hEDS (hypermobile Ehlers-Danlos syndrome[19]) in April 2024. I have been struggling for over a decade. But Leeds Teaching Hospitals Trust Rheumatology department has recently decided not to support and treat patients with hypermobility disorders. My GP told me this just this week. There are no specialists. GPs say 'I don't know anything about hEDS, you need to see someone who does' but there's no one to refer us to. The doctor who diagnosed me has left. I'm in pain every day, I struggle with fatigue every day and no one knows what to do.

I'm researching it all myself and figuring it out on my own with charity help but when I go back to the NHS with the information given to me they still don't know what to do.

I'm frightened , I can't work full time, I can't get benefits, I'm struggling with my mobility. When it's very bad I'm housebound. I have MCAS (Mast Cell Activation Syndrome[20]) symptoms and was hospitalised last year but Leeds Teaching Hospital Trust says MCAS is 'too controversial' so they won't help. They still do not know what happened to me last year. I was incapacitated for six months. No one understands my health condition and I'd be homeless by now without my partner and family.

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[19] https://www.nhs.uk/conditions/ehlers-danlos-syndromes/

[20] https://www.potsuk.org/about-pots/associated-conditions/mcas/

Personal stories: ‘I thought they could be linked’ – Thea‘s story

I contacted my local surgery about a women’s health issue in summer 2024. I was given an in-person appointment with a women’s health doctor which I was grateful for. She’s been very supportive over the past few months. However, no mention was made of my chronic illness or mental ill health even though I thought they could be linked. I ended up having to see two different doctors over a number of months for separate symptoms.

Personal stories: ‘Inadequate care for ME/CFS’ – Jenny’s story

There is inadequate specialist care for people with ME/CFS and little understanding on behalf of GPs. The NICE guidelines were updated in Oct 2021, but GPs are not educated about the condition (or worse still have unfounded and inaccurate assumptions that ME is psychological illness). In fact dismissal by HCPs is a key point mentioned in the NICE guidelines.

The Yorkshire Fatigue Clinic is staffed by OTs and offers only guidance for pacing. It conducts no tests and has no specialist physicians to investigate or provide care related to the many physiological aspects of the illness. The Yorkshire Fatigue clinic does not accept self-referrals and was reduced in size this year on the retirement of its clinical lead, thus reducing patient access. GPs have no specialists that they can refer people with ME to for further investigations and offer very limited care options. There are no specialists to whom I can go to get informed views about symptomatic treatment of my illness.

This is a highly debilitating illness, but there are some symptomatic treatment options that could be tried if one had access to a supportive and knowledgeable physician but there are none. The NICE guidance calls for specialist multidisciplinary teams and for patients to have care plans and annual reviews, but this just isn't happening! I have asked all three local GP practices and there are no GPs with special interest in this disease.

Personal stories: 'Disappointed, alone and afraid' - Yasmin's story

I've had problems walking for nearly five years, so my doctor referred me to the neurologist at York Hospital (I've been told there's only one). I waited 15 months then managed to get a last-minute appointment in March.

I explained my mobility issues to the neurologist, as well as the leg pain and cognitive issues, and was asked to do some physical activities, like hopping on the spot. I was told my brain and spine were fine, and to use graded exercise to improve my walking (with no mention of the other issues), in what I felt to be quite a patronising manner (I'm sure they would have spoken to an older male patient differently).

I've tried so hard to exercise more but it leaves me exhausted and in more pain (in fact, I've read in ME books and online that graded exercise shouldn't be used). I felt unable to reply to the neurologist, and left feeling very disappointed, alone, and afraid.

I know ME is a difficult condition to treat, and I'm not expecting a cure, but it would be nice if medical experts took it more seriously. It worries me to think there are other ME patients on the waiting list for the neurologist who will likewise leave disappointed.

Personal stories: ‘Worried about waiting times’ – Kai’s story

I have a prolapse. I need my pessary replacing every six months. This procedure needs to be done at the hospital. Waiting times vary; for York it’s 15 months, Selby eight months and Harrogate four months. I opted for Harrogate not knowing that by doing that, I will always have to go to Harrogate for the pessary replacement. I didn't want to do this forever and I have managed to get back on the York list, but I am worried about the waiting times which mean the pessary won't be replaced as regularly as required. I wonder why a GP can't do this instead?

Concerns about osteoporosis care

Representatives from the York branch of the National Osteoporosis Society raised concerns about osteoporosis care. They are hearing from members across York that GPs are not following protocols in osteoporosis care. They are concerned that people are being kept on treatments for too long. For example they are aware of people being on Alendronic Acid for far longer than the recommended five years. They also flagged concerns about the lack of a fracture liaison service in the city. They believe there is significant need for this service that would help to support people and prevent future fractures. However, a previous service in York stopped due to a lack of funding. Prior to Covid, some GP practices had an osteoperosis lead, but this also seems to have been lost.

Concerns shared with Healthwatch York.

Personal stories: ‘Never taken a break’ – Lucy’s story

I’ve been taking Alendronic Acid, for osteoporosis, since 2009 and have never taken a break from it. When I recently saw a specialist they were surprised I was still on the medication. They told me I was one of three people they’ve seen that have taken the medication for this long. I should have had regular reviews for the medication and had breaks from the medication. But my GP has never been in touch to arrange a review - they have continued to prescribe the medication on a regular basis. As a result of taking the medication for such a long time, the specialist told me that other treatments may not be open to me if a test I’m due shows that my osteoporosis has developed further. My daughter also has osteoporosis, but she lives in West Yorkshire. She has received annual medication checks and was advised to have breaks from taking Alendronic Acid.

Personal stories: ‘Lazy’ - Diana‘s story

I have MS and first went to the GP with symptoms of fatigue. I was told I was lazy and had to do more exercise.

Personal stories: ‘Dismissed’ - Kitty‘s story

My wife had an issue with fatigue and was dismissed by the doctors. She was feeling tired even after 10 hours of sleep. She had blood tests and was referred to the eye clinic (but didn’t know why). They then referred her to the diabetes nurse without explanation and she was diagnosed as having type 2 diabetes. She is not at all overweight. However, the GP explained the next steps to her about losing weight etc. It was later that they said that she actually had type 1 diabetes.

Personal stories: 'Long term damage' - Poppy's story

> I also went to the GP with fatigue and was told I was lazy and to push through it. I think this has led to long term damage.

Personal stories: 'Growing pains' - Sam's story

> I had chronic pain for years. I went to see a hospital doctor who said I was overweight and it was growing pains.

Further issues shared with Healthwatch York regarding long term conditions.

Women taking part in the Healthwatch York volCeS meeting exploring women's health wanted to see greater acknowledgement that women live beyond the menopause. They want to see a much greater focus on health issues affecting older women including bone health and recognising osteoporosis, nutrition, and wound management.

Mental health concerns

> *I don't know if it is my gender, age or something else, but I've been unable to get support for my restrictive eating disorder. Doctors and nurses have told me I'm underweight but not severely. But eating disorders are about much more than weight. Talking therapies have also told me they don't provide help for eating disorders.*

Personal stories: 'I wasn't confident' – Frankie's story

I was referred to a mental health care coordinator by my GP as a result of a shutdown in the GP practice waiting room. I wasn't confident that the care coordinator would provide any help and I was right. Their approach was to say that life is not always easy and there are ups and downs. This despite knowing I had struggled with mental health issues including an eating disorder as well as having an autism diagnosis.

When we discussed my eating disorder and I talked about the limited calories I was eating the care coordinator didn't really comment or offer any support to try and address the issue to have a healthier diet. They just said I can solve my own problems and I know what I am doing. I'm on a waiting list for support but there's a two year wait. I had asked to be referred to a dietitian but this has never happened. The care coordinator sent a letter summarising the appointment and offered to amend anything which needed it. I was grateful for that as in my eyes the letter didn't reflect the appointment.

Personal stories: ‘Hysterical woman disease’– Isla‘s story

I’m one of the York women with a misdiagnosis of BPD (borderline personality disorder.) It’s happened to me but I also know so many women who’ve had this as well. It’s basically ‘hysterical woman’ disease. I got this diagnosis back when Bootham existed. I went to my GP saying “There’s something wrong.” First thing was “do you want some drugs?” No, I want a diagnosis. I was taken to Bootham, spoke to two women for an hour and got a BPD diagnosis.

I spent a lot of time questioning it. “This doesn’t feel like me.” I started reading stuff about neurodiversity. I spoke to a good mental health nurse. He said “I think you’re autistic.” I also read stuff about CPTSD (complex post-traumatic stress disorder). I started asking questions about support and misdiagnosis. I was very clear I’d spoken to health professionals who believed it was autism and CPTSD. Mental health services said “who told you that?” When I said a GP and nurse, this was not good enough. I needed to go back to a GP for a new diagnosis and they wouldn’t do this. They just kept bumping up the Sertraline. Every time I’d say “I’m sad” and they’d increase the dose. Then they prescribed me another SSRI alongside Sertraline – for insomnia. It knocked me out, You can’t be sad if you’re unconscious I guess.

I decided to stop the anti-depressants. They make you put on weight, they make you “dull”. Without them my moods are spikier, I do get panic attacks but I’m better. I’m not anti-meds, but they need to be the right ones.

Eventually the GP agreed it was time for a different diagnosis. But York had lost its diagnostician. So I went private, and the doctor said CPTSD immediately. This was updated on my mental health records.

Then I received a letter from the eye clinic. My BPD diagnosis was still on it. So I went back to my GP and said “you need to remove this. It’s wrong and there’s lots of negative assumptions about this.” The GP said “But a doctor diagnosed you with this.” I replied “She also said I was wearing Doc Martens and she was wrong about that.” But they still won’t remove it from the record.

This is a massive issue for women. I had a friend who went to hospital with an injury. The nurse said “There’s a BPD diagnosis on your record, you did it to yourself.”

I understand empathy fatigue is a thing. It must be a miserable job at times and people doing it are not treated well enough. We need to support them well enough so that they can do their jobs with empathy.

I had a really bad experience with a GP. I went about a mental health issue. He could see the diagnosis on the screen. He said “I’m not going to help you. People like you scamming the Government, claiming benefits.” I left in tears. My partner went in, and the receptionist said “oh yes, that’s him, he’s bad with mental health, we’ll take him off the list of people you’ll see.”

Concerns about lack of support and inappropriate referrals

Women are going to the women's centre after contacting the crisis line. They say that the crisis line has referred them to the women's centre for support. The women's centre keep telling mental health services that this is not appropriate. They can't support people in crisis - that is the role of the crisis team. The referrals stop for a few weeks and then start again. The centre supports women who have tried to take their own lives on more than one occasion and who say that the crisis team has said they can't help. The women's centre team often have to take women to A&E because there is no other option and no support available from the crisis team.

Concerns shared with Healthwatch York.

Medical misogyny

> *I often feel, as a woman, any medical issue is brushed over as 'just being a woman' or 'it's because you're on birth control'*

Personal stories: 'Ignored' – Wendy's story

If my son needs any healthcare input from the GP now I get my husband to take him as I am usually ignored where my husband is not. I have to write out what he needs to talk about as I am the main carer. But time after time, I am ignored so I've given up.

Personal stories: 'Anti-female bias' – Jamie's story

Getting my, female, health issues taken seriously. There seems to be an anti-female bias. My husband and I had the same symptoms. We both went to the GP to see different doctors. He was told that it was difficult for him, was given seven days of antibiotics and told to come back if things got worse. I was told that this was usual for women, I should get over it and was given three days of antibiotics. One male GP told me I'd have to see a female GP. Another said, 'you don't know how much is in your head'."

Personal stories: ‘Didn’t believe them’ - May’s story

> My partner went to the GP for help. They were anorexic, but the GP didn’t believe them as they were wearing a big coat and the GP didn’t ask them to take it off.

A number of people went to the GP with different symptoms and were told ‘it’s your hormones’. But even if it is hormones, there are symptoms. Surely something could be done?

Further feedback shared with Healthwatch York

Women taking part in the Healthwatch York voICeS meeting exploring women’s health wanted to highlight the impact of caring, and ‘women’s load’ – the cognitive load many women feel they have to carry on behalf of their family. Many highlighted that societal attitudes towards child-rearing and caring for family members add to the challenges women experience.

Navigating health and care

> *Every time I have phoned the health visitor (single point of contact number) about anything they just tell you to go to your GP so there's no point in ringing them.*

Personal stories: 'Extremely helpful' - Xena's story

I have often had to book nurse appointments about women's health checks and issues and have found them all to be extremely helpful. They always seem to be running on time, are friendly and positive, give reassuring and personalised information and are thorough and efficient.

Personal stories: '"You can buy it at Tesco"' - Margaret's story

I bought something to help with women's issues at the pharmacy. I was later told I could get it on prescription. I am a pensioner and couldn't afford to keep buying it. I went to the GP practice to ask about getting it on prescription. The receptionist told me that 'you can buy it at Tesco'. Later I had a phone call with a GP about another issue and mentioned this to them. My GP said he would arrange for me to get it on prescription.

Concerns about safety and access to care for women

Workers at the women's drop in talked about the challenges of some of the people they work with going to A&E. The chaos, noise and general atmosphere can put them off. They are also very worried about who they might meet there and that they may meet their perpetrators. They believe a designated safe space for women to wait in, which would be a women-only space, could help increase access.

Concerns shared with Healthwatch York

Recommendations

Recommendation	To
Improve training around recognising tongue ties in newborn infants and make sure staff are aware of and able to put people onto the pathway for correcting this.	York & Scarborough Hospital Foundation Trust / City of York Council Health Visitors
Encourage local clinicians to take up opportunities to improve their knowledge and understanding of long term conditions such as ME / CFS and Endometriosis, including how this presents in younger women.	Humber and North Yorkshire Health and Care Partnership
Provide clarity about the pathway for women in our area with hEDS and POTS	Humber and North Yorkshire Health and Care Partnership
Continue to make a case for locating a Mother and Baby Unit in Humber and North Yorkshire with national health bodies	Humber and North Yorkshire Health and Care Partnership; Mental Health, Learning Disability and Autism Provider Collaborative; NHS England Specialised Commissioning.
Review the local pathway for women's bone health	York Health and Care Partnership

Initial response from

Women Living Well Longer, Humber and North Yorkshire Health and Care Partnership

With reference to Kai’s story, Humber and North Yorkshire ICB introduced a new locally enhanced service (LES) for GP practices for pessary fitting from April 2025, alongside an IUCD fitting and removal LES.
Kai would now be able to access pessary fitting at her local GPs. There has been excellent provision in York from the introduction. In April 102 women had pessary fitting at York practices and in May 109.

For Jodie, Gemma and Angie's stories, what each of them really needed was a good, holistic first menopause appointment with a knowledgeable GP. Providing menopause care in line with the BMS vision for menopause care[21] would mean that women got the care they needed first time. The work we've delivered on Women Living Well Longer supports this, with clinicians undertaking the BMS Management of Menopause Certificate and accessing a monthly multi-disciplinary team meeting led by a consultant gynaecologist where there is discussion of themes in menopause care. The funding we've used for this work will be spent by August.

Jennifer Allott

Strategic Lead – Women Living Well Longer Programme

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[21] https://bit.ly/BMSMenopause

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