


**“Talk to Us”
Women’s Health**

**Phase One
Supplementary Report
Personal Experience
Case Studies**



Introduction

This report features 11 personal experience case studies collected during Phase 1 of our 'Talk to Us - Women's Health' project. Each case study highlights key healthcare challenges women face, particularly when dealing with women-specific health concerns. These case studies, along with responses from 305 survey participants, informed our 'Women's Health Exploratory Survey' report, which can be found on our website. The present report is intended as a supplement to the Exploratory Survey.

We are grateful to the many women who shared their personal experience with us. Each personal experience featured below is introduced with an overview of the key themes it addresses.



Personal Experience 1

Key themes

- Feeling unheard
- Access to services
- Lack of information
- Mental Health
- Menopause

“As far as I am aware, there is no Well Women clinic at our GP practice. I wouldn't know where to begin if I wanted to speak to someone specifically about women's health. Getting appointments at my GP Practice can be difficult. When you contact the reception in the morning, all the appointments have gone. Sometimes I call to talk about concerns, but I give up as I feel that I am bothering them. This means that I often don't speak about my concerns with a health professional and issues are ignored.

I am [in my mid-sixties] and couldn't tell you if I have been through the menopause, I have had no checks, support or reassurance from my GP practice. There is nothing specific that I know of that offers advice around this. I am constantly seeing in the news and on TV people talking about women's health, but there is nowhere near me that I can go to for advice. I am trying to keep myself fit and do the best I can, but there isn't any reassurance that what I am doing is the right thing to keep myself healthy.

It would be great to talk to someone about post menopause, what to expect, what will happen to my bones. For example, urine incontinence, it is on the tv, but there is nothing at my surgery where I can discuss what the treatments are. When I talk to my friends or people in the gym classes, I know there are loads of women experiencing urine incontinence, but again I would not know where to go for support around this.

Women's mental health - as you get older you try to be the 'mother hen', and it is hard to let that go when your family go on to leave home, have children themselves, etc. This is something a lot of women go through, but there is nothing there to discuss this change or support women experiencing it, and it does have an effect on your mental health. It's something that we are expected to get on with and find a way through ourselves.

There is inconsistency around the country with NHS services. My sister lives down south and her doctors offer a Well Women's clinic, MOT check-ups, and mindfulness services. Why can this not be the same everywhere?



Personal Experience 2

Key themes

- Poor experience of care
- Gynaecology

I had a horrific gynae internal examination at the hospital. It was brutal and degrading. I should have made a complaint at the time but was very traumatised by the experience.

When I was told last year I needed to have a camera inserted into my womb again due to a post-menopausal bleed, I was naturally very apprehensive. I explained my previous experience to the doctor, and she was shocked, but very kind and gentle. She couldn't get the camera through my cervix and didn't want to cause discomfort so advised me I'd needed to go back and have a general anaesthetic for the procedure, and hopefully they'd be able to remove the growth at the same time.

Previously the consultant (female) had forced the camera through my very tight cervix, and was very dismissive of the extreme pain that I was in. There was a fair amount of blood. The nurse could see how much pain I was in and came around to hold my hand and talk to me. I was then sent into the adjoining room where my husband was waiting, naked from the waist down with a piece of blue paper 'to clean myself up' at the washbasin in there. It was totally degrading and embarrassing, I was shaking, and my husband was also in shock having heard me in pain and the sight when I walked through the door.

I went back last year for the GA, and everyone was very kind and caring. It was a totally different experience. Unfortunately, the growth couldn't be removed at that time and I returned last September for a robotic assisted full hysterectomy. All went very well, and I was home the next day. All staff, theatre and on the ward were fantastic. So helpful, caring and understanding. I was much relieved and very grateful.



Personal Experience 3

Key themes

- Gynaecology
- Endometriosis
- Poor experience of care

In 2022, I requested a laparoscopy due to severe symptoms and pain, suspecting a gynaecological issue. Following the diagnostic laparoscopy, I was diagnosed with endometriosis. Despite the surgery my pain persisted, particularly in my bowels. When I inquired with consultant if my bowels were examined, I was informed that nothing was detected. Consequently, I was referred to the gastroenterology department for a colonoscopy, despite my symptoms not aligning with a colon issue. During this procedure, diverticulitis and a polyp was found and removed, yet my pain remained. This led to a referral back to gynaecology.

My consultant prescribed various medications, none of which alleviated my pain. After discussing the possibility of a hysterectomy with my GP, I was advised that it might be appropriate. However, my consultant initially dismissed this option due to being too young and potential long-term effects, though he did not rule it out entirely for the future.

Despite my ongoing severe bowel pain, I requested an MRI but was instead given Zoladex to suppress my ovaries. My GP referred me for a second opinion from another consultant, who agreed that a hysterectomy was necessary due to my endometriosis. Subsequently, I was placed on the waiting list for the surgery.

When my Zoladex treatment concluded I remained in constant pain. I contacted my consultants' secretary, requesting to resume the treatment, but was informed that I couldn't due to risks associated with taking it for longer than six months. My surgery was scheduled to take place two months later.

On the day of the surgery, after receiving epidural and general anaesthesia, I woke up to find that the surgery had not been performed. As I was transferred to the ward I repeatedly asked for an explanation, but none was provided. Later in the evening I was told that my consultant had attempted to ring me on my phone to explain, but as I had not answered I would need to wait until the next day. I found this extremely unprofessional. A doctor should not be calling me on a private number to have a conversation that should be conducted face-to-face. The following day, I was told to resume the Zoladex treatment as part of senior consultants' treatment plan, despite being told previously that this was too dangerous. I also requested an MRI and was given an appointment for this and then discharged.

My consultant later apologized, explaining that the surgery was aborted due to some unexpected complexities. This entire ordeal has left me in continuous pain and has significantly impacted my quality of life. My surgery has been rescheduled twice, and both times it ended up being cancelled - once after I spent 7 hours waiting in the hospital without eating all day.

This entire experience has left me feeling abandoned by the NHS and without confidence in the care I am receiving. No patient should endure constant severe pain and the emotional toll that accompanies such a prolonged and poorly managed medical journey.

Personal Experience 4

Key themes

- **Menopause**
- **Mental health**
- **Lack of information**

I have been going through the menopause and the last couple of years have been awful. I was given HRT, which I wanted to help reduce the risk of osteoporosis etc., but I started getting lots of lumps which were appearing quite aggressively. There is breast cancer in my family, and I'm due a cervical scan so as you can imagine I'm quite anxious and stressed about it. I was taken off HRT for my health, although some medical professionals say I can take it while others say I can't – it's very unclear.

There is no consistency in information provided by healthcare professionals. I have a healthcare background and it's still confusing, I can't imagine what it's like for someone who doesn't. Everything I've learnt is from my own research or speaking with other people who have gone through it, and that's all confusing too.

I've discovered a holistic approach which seems to be helping, but because it's not a prescribed medication I am always worried that I'm taking too much/not enough. I have also put on a lot of weight in a very short time. I have never had a problem with my weight, so this change is really worrying. However, when I spoke with my GP, they just shrugged it off and said I look fine. This all adds to the psychological impact, but doesn't seem to be seen as important. I've had no health and wellbeing advice or support on how to lose weight.

The whole thing has been like a domino effect with one thing after another going wrong. The health and the psychological impacts have been massive.

I was widowed a few years ago, and I don't always know whether what I am feeling is bereavement or the menopause, what is normal and what isn't, and when I should worry and see my GP. I have felt very alone.

An information pack which talks about both being on HRT treatment and when not on HRT, with guidance on what is normal and when people should be concerned, would be really beneficial. This could be available at GPs, pharmacies and other places so that women had clear, consistent information easily available and not have so much conflicting, confusing advice.



Personal Experience 5

Key themes

- Access to services
 - Screening services
 - Lack of information
 - Lack of expertise
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I'm in my 70s and, luckily, fit and healthy, so I don't need to access health services very often. But I feel that if I needed to, it's no longer as easy as it used to be. I don't get invited for breast screening any more, which makes it harder to access.

Most of the women I know with breast cancer were aged 70 or over, so I don't think it's a good system. Instead, it would be better if they continued to mail out appointments, and if we wanted to opt out of them then we could do so. I opted out of cervical smears when I was 60 because all my risks are very low, I've never had any problems, and I'm fairly alert to anything that would change. But I do still want breast screening. I've only tried to call up once and I just got an answerphone asking me to call back. I've not done it yet, but I will.

It's happening with a lot of services. I'll get a text from my GP practice saying I need to make an appointment for a shingles vaccine. So I'll call up and then they'll tell me there is no vaccine, and I just need to keep ringing up. It's not a very good system. One time I managed to get an appointment for a shingles vaccine, but it was cancelled on the morning due to sickness. I understand that. But they didn't send another appointment through, and when I called up they told me again that there is no vaccine at the minute. There's a whole climate now where

one thing is meant to happen but it can't, because the provision isn't there. So why bother to ask me? It happens with my blood tests too. I have high cholesterol and I'm under care at the hospital because I'm at risk of glaucoma, so I'm meant to have these tests every year. I used to get a call but now it's down to me. I happen to be a woman, but it must be happening to men as well.

Fortunately, my glaucoma situation is very stable, and I am getting good preventative medicine at the hospital. It was an optician who picked it up and they referred me to the hospital. They said it's not glaucoma, but there are two drains in each eye and mine are very narrow, and that can cause glaucoma. When they discovered that, they drilled a hole in each eye with a laser. Now I go every year to make sure it's OK. That's because there is glaucoma in my family. I don't see the same person every time but that's fine, I feel confident they know what they're looking at. They've been totally proactive: they send me appointments, I go, and we've never had a problem. I think the system is under huge stress. If I went to my practice and said "X has happened", I probably would get to see somebody, but if I want to talk, they haven't got the time. So, you end up with situations where someone is given the job of just dealing with you, but they tell you the wrong thing.

I called up my practice because I'd had a really bad throat infection for over a fortnight. I'd already had some antibiotics, but it hadn't cleared. The practice nurse said it's because it's a virus and I didn't need to see the doctor. But in the past, I've had quinsy, where your throat becomes so infected you can't breathe. If it's not treated you can end up needing a tracheostomy, and I had to go into hospital to get antibiotics delivered directly into my throat. When I told her that it made a difference. But I had to be very directive to a professional, and not everyone can do that. Some people don't have somebody to advocate for them, or have a strong voice themselves.

Overall, I think women need someone within their practice who they can speak to if needed, about all sorts of different things. That used to be the role of a health visitor or district nurse. Now that's all been put out to Virgin Care, and they just tick a few boxes. Even for younger women, if there was somebody in the practice who understood women's needs, that would make a huge difference. It's probably not just women, but I do think we need that for women in particular. I have a daughter, and she has young children, and some of the treatment they've had has been awful. The practice won't respond, and when they do, they're given the wrong information. She was referred to a pharmacy, and one pharmacist said one thing, and another pharmacist said another thing. And then the doctor rang up and said, "I think it's this". But thinking isn't good enough, you need to see somebody. During COVID, I understand they did their best, with sending photos and consulting on the phone. But now face to face appointments are so rationed, it feels like the last thing they want to do is see patients.



Personal Experience 6

Key themes

- Autism

There are things I need help from the doctors with, but I am anxious to call them because of my autism, and because they've been dismissive in the past. I was diagnosed with autism two or three years ago. I always knew I was autistic. I have a comfort blanket that I can't sleep without, and I brought that to my appointment. I felt anxious going to the appointment, but also a bit excited. Now that I have a diagnosis, it has helped me because it's made it easier for me to know and accept that I have autism.

My mum thinks I have ADHD as well, but I haven't been diagnosed for that. Sometimes I am hyper, and sometimes my mind is running. Sometimes I do impulsive things. When I went to my autism diagnosis, I had to sit there, but I couldn't stop moving about and fidgeting. I keep side-tracking in college because I don't get help with my work, and it's hard to concentrate. They aren't giving me the support I need. But I don't think being a woman has affected how people treat me with my neurodiversity, people understand and are patient. I feel anxious talking to people on the phone, and that makes it difficult for me to get to the doctors. I need to go because of my feet, but I feel anxious about calling them up.

I also worry that they will be dismissive about some things. I went to the doctor ages ago because I have a lump near my breast. They took a look at it and gave me some pictures of what it could be, but it didn't really look the same. So, they just left me with it to see how I got on, but they've never called up to see if anything has changed. I felt gutted. It hurts when I walk, and I need to stop for a breather. I probably will follow up with them at some point.

I have a body image issue as well, but I don't think I'll talk to the doctors about that. I have a pouch on my stomach that I am trying to get rid of, but I think if I call them up, the doctors and nurses will just tell me to get exercise or eat healthily, which I do anyway. I just need some advice for nutrition and movement that's not dismissive or judgemental.



Personal Experience 7

Key themes

- Gynaecology
- Poor experience of care

Three months ago, I had a traumatic hysteroscopy. The experience obliterated the trust I had, and I'm still traumatised today. I still can't talk about it without crying. Since then, I have spoken to other women, who have also shared their stories of the pain and shame caused by this procedure.

I went to my doctor because I had been experiencing post-menopausal bleeding. They told me this could be associated with cancer, and they referred me to a gynaecology pathway. I got a call to arrange a scan, and then I was given a clinic appointment. On that call, there was no mention of any procedure. I received a letter to confirm my appointment, and in that letter there was also no mention of any procedure, or any of the information I would need to make an informed decision.

After the scan I was told that the lining of my uterus was thicker than it should have been and that I needed to have a hysteroscopy, which I'd never heard of before. They said they would do it as an outpatient procedure, and that a tiny camera would be inserted through my cervix and into my uterus, and they may take some biopsies. I was told it would feel like period cramps.

I had no time to educate myself about the procedure. I believed what they told me, and consented to it, and I went into the room, and they started the procedure. As soon as they started, it was really, really painful. A brutal, searing pain. The hysteroscopist couldn't access my uterus [due to complexities]. They went and got a registrar to continue the procedure.

I had four people looking between my legs while I was in incredible pain. I've had three babies with no pain relief, and this didn't compare. The pain took my breath away. I was crying and making noises, but they continued with the procedure. I got to the state where I couldn't talk, I wanted to tell them to stop but I couldn't get the words to come out of my mouth. Eventually I was able to tell them to stop, and the nurse had to repeat that to the registrar before they finally stopped. But I shouldn't have had to tell them, they could see how distressed I was.

The registrar stormed out of the room, making some comment about not meaning to hurt me, then two of the nurses left, then the third one. I was left to compose myself. And then I saw the bloody scalpel on the tray next to me, and I fixated on it. I consented to a camera, not a scalpel. I was never told they were going to try and cut their way in.

My legs felt like jelly while I tried to get dressed. Eventually the first nurse came back and shoved a consent form in front of me. I was bleeding, but I wasn't offered any sanitary wear. I was told that most women tolerate the procedure, and I was made to feel like I was the only person who experienced this pain. It was so traumatic, I couldn't speak about it for three days, and then I finally broke down.

Because I had stopped them, they weren't able to get through the cervix into the womb, and so I needed to get the procedure done a second time. If it wasn't for my family, I would not have gone back. This time I was sent to a different team, and the procedure was to be completed by a gynaecological oncologist, instead of a hysteroscopist and registrar like the last time. And this time, I was going to be given a general anaesthetic.

I was petrified. I went with my husband, and I cried when the doctor came to see me. I told her I understood I would be under general anaesthetic, but I knew what she was going to do to me. I still had that image in my head, the bloody scalpel, the searing pain. I've never been frightened of a procedure under general anaesthetic before.

The second team was lovely. The gynaecological oncologist told me there have been lots of problems with these hysteroscopies in outpatients, and the anaesthesiology team said they get a lot of women coming through who need a general anaesthetic. They could see how traumatised I was, and although I was frightened, it wasn't their fault. They told me they won't force their way in, and that if they couldn't get to my uterus they would look for other ways to find out what was going on. I was given intravenous pain relief before I was given the general anaesthetic. It should be given as standard. In outpatients, I wasn't offered anything. The gynaecological oncologist and her team finished the procedure successfully. They took biopsies, and everything came back clear.

After my experience, I did research online, and talked to other women. If you search for 'hysteroscopy', the official narrative makes it sound straightforward, but if you look for 'hysteroscopy trauma', you will find the stories of other women. I shared my story online, very publicly. It's important because if people know what's going on, they can demand pain relief, and they can advocate for themselves. And from all the women who've come forward to talk to me, none of them have told me they've had an OK experience. There's a campaign group online, and gynaecologists and manufacturers have called them a 'barrier' to this procedure. But all we want is pain free options. I've made an official complaint to the hospital, and sent copies to my local MP, and the Secretary of State for Health and Social Care. I'm currently waiting for the PALS service at [the hospital] to respond.

It was so scary when it was happening because I couldn't do anything. And it's still affecting me. I have another gynaecological problem that will come up in the future, but I don't know if I'll go to the hospital about that. It's not life threatening, but it is uncomfortable. But I don't want to put myself in that position again. I can't think of anything that can be done to restore that trust. I've had such good experiences in the past and nobody has ever made me feel like this.

Really, I should have been told I would be having a procedure beforehand. I should have been told of the risks of the pain, they know it's a chance, our stories are out there. Some people only get cramps but it's important to be warned, and offered the right level of pain medication. I shouldn't have been left in the state I am in now. I was so relaxed going into that room, I had no reason to doubt what they were telling me. How can they say that was informed consent?



Personal Experience 8

Key themes

- Lack of information
 - Lack of expertise
 - Menopause
 - Talking about women's health
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A few years ago, I went to the doctors and learned I might be going through perimenopause. I'm now in menopause and steady on my HRT, and I have a nurse I can trust. But I've had to do a lot of my own research, and at one point I was prescribed the wrong patches.

I went to my GP and talked about the symptoms I was having at the time. At first, I thought it might have been low blood sugar, but then I realised over time how I had started with hot flushes. The nurse said it might be perimenopause, and they gave me a leaflet. I suffered with really heavy periods, and I never really thought about it until I started learning about perimenopause and menopause and noticing my menopause symptoms later on.

When I went to the GP about menopause, they didn't know much about it, or what my options were for HRT. They were really dismissive about HRT, and just focused on the risks and not the benefits.

I'm a nurse, so I managed to find the information I needed myself. I went to the NICE guidelines, and that was when a lot of publications were coming out about the benefits of HRT. I spoke to a couple of GPs, but they weren't well informed, and they couldn't signpost me. Eventually I was able to get to a place where I was well versed in my head about the choice I wanted to take, and I started on HRT.

Around 2020, there was an international shortage of HRT patches. I was prescribed a specific brand of patch, and I would go to the pharmacy and they would say they didn't have it, and I would need to get a different prescription. Or I was going on safari around all the different pharmacies trying to find one which had what I needed. I know some people who just went without HRT because they couldn't access it.

I rang my GP and told them I needed a different brand but with equivalent hormones. I needed a combi patch at the time because I had a cyclical regime with periods. It's important early on in menopause, because if you only take oestrogen, it has a higher risk of uterine cancer, and the dual patches with a progestogen protect you from that. But they prescribed me an oestrogen-only patch instead. I took it back to the GP without using it and said I don't think this is right, and I talked to the pharmacist and they agreed. I do clinical incident reporting, and this was a drug error. It makes you worried. I have extensive clinical knowledge and was able to spot this, but not everybody can do that. We're relying on professionals who don't know.

There are other things that happen as we get older, and where we need better education and signposting. I've been reading about stress incontinence, and how for people who've had children through a small birth canal, it can cause a lot of problems later in life.

Bone health is also really important. When my mum was alive, she was 5'4", and by the time she died she was 4'11", she lost a lot of body height through osteoporosis. There's lots of evidence that low fat food is not the best. We need a lot of calcium, but we should also be eating full fat yoghurt and cottage cheese, and making sure we get lots of protein. Dieting is causing so many problems, whereas a healthy diet, that's the information you need to help protect your bones.

I know so many colleagues at work, and friends, who have told me about their symptoms, and I've asked them if they've thought about getting advice on menopause and HRT. And I've signposted people to the NICE guidelines as well. Quite a few people have come back and said it's transformed their lives. Lots of women are suffering. My mum went on for years having hot flushes, and I didn't want to go through that.

The biggest thing that's helped me is meeting a nurse I can talk to, and almost being given permission to contact them directly. Contacting a specific healthcare professional through your GP practice is difficult, you just get randomly assigned. But I've been able to go back to this person who I trust. There's a lot of trial and error for managing symptoms. I had my HRT increased to cover my symptoms, but it actually made them worse, and I had to reduce my HRT myself. But I trust her, and I feel like I can go back and say, we did this last time, but this is happening, this is what I've found out. I can call up and get an appointment quickly. And it's usually in the evenings which is really accessible for busy women who are working full time. Having that extended, flexible capacity to see patients is important.

We don't get much continuity in the health service because of the nature of GP practices, but it makes such a difference. Particularly for elderly people, seeing the same GP or practice nurse each time, and not having to tell your story every time. That's what happens in healthcare, we get so many complaints where someone comes in, and we've never seen them before, so they have to tell us their whole life story, repeating the same things over and over again. We need continuity of care, and personalised care, it's what people want and we should facilitate it. People stick to a formula instead of looking to individual patients, it's about tailoring advice to each patient. And it would be safer in the long run, because you already know the individual and trust them.

How do we promote healthy aging for women? We need to talk more about women's health in society as well. We should talk about it in the workplace and in schools. We don't talk about the effects of menopause in the workplace. We

don't talk about periods, even in 2024 that's a bit taboo in a lot of ways. So that makes it very hard to talk about when things start to change. It's about getting better information, and making it readily available to women at all stages of life. Making sure people know these things are normal, what they might experience, what their options are, signposting, and allowing people to make an informed decision about if and how they want to manage their symptoms

We have Menopause Cafés in Cumbria, but I don't think it's from health professionals, I think it's women like me who've seen our mothers suffer, and are learning that we can do things to keep ourselves healthy. But it takes a lot of courage to go. We need to talk about these things more.



Personal Experience 9

Key themes

- Cancer
- Screening services

By my mid-50s, I'd had two cancer diagnoses. In my family, there is a long history of cancer in women and heart disease in men. I'm fortunate to have had some really good experiences of healthcare, but there is still a lot that needs to be done, especially around screening, and removing the fear about cancer.

Years ago I had a melanoma that was misdiagnosed at first. A second nurse had a look at it and picked it up, and they had me fast tracked, and it was removed in 48 hours. My son had got a new iPhone, and he was able to use the camera to take a photo of it, it was on my back. When I went for treatment, they told me, "your son has saved your life".

More recently I had breast cancer. When they found it the first time, it was very deep in my breast tissue, it was almost touching my lung, and every time at the hospital it was always difficult for them to spot, sometimes they had to get two radiographers. In my area we have mobile breast screening every three years, but my cancer grew between my regular scans. I always wonder if my breast cancer could have been found if the screening was more in depth, or if it was more frequent. Maybe it could have been picked up earlier? I knew an obstetrician once who couldn't believe that cervical screening in the UK is so infrequent, every three years or five years after a certain age. They thought that should be more frequent too.

I think a lot of people are reluctant to get screened because they are fearful of what the results will be. There's lots of advice on checking yourself, but people think it doesn't apply to them, it can't happen to them, some because of fear. But the earlier you find these things, the better the prognosis. And it's about knowing the support is there as well. The GP I saw this time summed a lot of it up, I said "you have to get on with things, it's tough, it's hard, but you have to get on", and she said "you have to get on with things, but with us at your side to support you", meaning the NHS. And the network in the NHS is good, if you've had cancer, they don't leave you. I've been fast tracked to gynaecology in the last few weeks, and I'm under rheumatology and orthopaedics for my bones, because of the side effects of my cancer treatment.

There's other support out there as well. There are charities like Macmillan that lots of people know about, but they might not know what support they offer, unless they've been affected by cancer through other people they know.

When I was in Blackpool Victoria Hospital, I saw queues of staff going for on the spot health checks: blood pressure, heart, cholesterol. It was available for all the staff working at the hospital, from cleaners to consultants. I thought it was great, to see the medics themselves queueing up for checks. We need more of these screening services out and about, in the work places, because if they're there, people will go to them.

Years ago, my husband had a prostate cancer screening at work, it was a blood test, and people could go any time in the day, which was good. I worked in a school for years and they were good, they had a pharmacy come in who checked our cholesterol and blood pressure. I had high blood pressure and cholesterol, and they recommended an appointment with the GP, and it was followed up, because we were given time in the work day. Would I have gone otherwise all those years ago? Probably not. Especially for younger people, they think "it's not going to happen to me", but it can. If these services are under your nose and promoted where you are, they'll get used. It's really important for

working women as well. Sometimes you can't get an appointment outside of work hours, and they can't always ask their employer, or they need the time for childcare. It's easy to think "I'll get it done, I'll get it done", but then you don't.

It's really important that we destigmatise cancer diagnoses as well. Even with doctors, that word, "cancer", they are reluctant to use it. I had a growth on my eyelid recently, so I went to dermatology, but they weren't sure what it was. They called someone else in, and they referred me to ophthalmics. I said to the doctor, "do you suspect it could be cancerous?" and he was a bit reluctant, he said "ooh, well yes I do actually". I'd rather know, and it's a good thing I knew because my referral was lost. I had to get on the phone to chase it up, and because I'd asked what type of cancer they thought it was, I could refer that info to the consultant.

There is a fear around cancer, but if the medics were more open about it, then perhaps that would destigmatise it. I was sent for some scans, MRIs, for my joints, and the consultant was lovely, but he was almost scared to death when I asked "so you're sending me to rule out any spread?" He was shocked that I'd asked the question. I understand that doctors don't want to put fear into patients until they've got the results, but there's this image attached to cancer that it's a death sentence, and if you catch it early, it isn't always.

The other thing that's really important is the relationships, and continuity of care. When I registered with my practice, my GP and I were both young, and we've grown old together. He knows our family history, and that makes a massive difference. My orthopaedic surgeon has recently left, and his replacement is good, but he knew me, we'd been working together for two years. He knew what he had done, what he was trying to do, what I can't have, shouldn't have. It was good. I go to the hospital for infusions for my bones, and I see the same nurse, they get to know you. Sometimes a one-off consultation, or a telephone consult, can be convenient, but it's not as good.

Personal Experience 10

Key themes

- Mental health
- Talking about women's health

The good thing about the mental health services is that they are becoming known, and the bad thing is that sometimes women don't get listened to and don't get taken seriously. I have had bad experiences with this, and so I tend not to talk about it anymore.

Some people don't seem to take mental health seriously when it comes to young women. We get told it is just hormones or that there isn't any reason for us to feel how we do. I feel if we are listened to more we can then feel more comfortable to approach health professionals and talk freely about the problems we are having with our own personal lives.

The more we are not listened to the worse mental health in young people will be, and the less likely it will be that young people will go to professionals to seek the support that they desperately need. I feel more work needs doing around mental health services for women, in order to provide support when we need it and most importantly to make sure that we are taken seriously.

Personal Experience 11

Key themes

- Access to services
- Long waiting times
- Not being heard

The biggest problem I have had is the same for everyone. Just getting access to the GP is a problem, and if you need to see a lady doctor you can't always get one without a delay. I find the doctors who are women only work part-time, which then gives you less time to see them and get an appointment with them. I was diagnosed with Lichen sclerosus, and I find with this condition you aren't always given the treatment you need straight away. I feel they bounce around the condition and don't treat the real issue, and they give you medication that doesn't always help. A lot of steroid creams are given, with no thought about how this affects your body.

I feel there is very patchy knowledge of this condition around Lancashire, and I feel I always need to explain my condition to professionals. I feel we are often dismissed and not listened to. I feel there is a slight postcode lottery to what treatment you get given by different professionals. More awareness of women's health conditions should be prioritised.

It affects both physical and mental health, and I feel there is no support or guidance on this. When I started with pelvic pain, my GP was incredible and did all the tests and then referred me to the pelvic floor team and it took months to get the first appointment. I got referred in January and I was seen in August, which I think was too long, especially with no support in the meantime. This made my mental health worsen, and I felt myself going into a downward spiral.

It started to affect my personal and social life whilst waiting for help and support. I had my appointment, but I wasn't examined even though I was expecting to do so. The person gave me exercises to do and then said I had to come back in two months. It did help over time, but this is massive chunks of time for me to be helped and supported. I had to do my own research on top of the hospital to help support me further. I feel I have sorted myself out instead of having professional help.

There are not enough staff to facilitate the clinics and wait times are very extensive and women are waiting months to access specialist clinics.

Personal Experience 11

Key themes

- Gynaecology
 - Long waiting times
 - Not being heard
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I'm unsure of how to word my account but hopefully this will suffice. I initially had continence issues in 2005, there then followed a series of therapies, physio and appointments, and probably two years later it was decided I was going to have a TVT (Tension-Free Vaginal Tape). I also had heavy bleeding, and a Thermal ablation in 2004 (this was succesful). My TVT worked, things ticked over well.

I started Menopause when I was 48, I had a blood test and when I called for results, I was told by receptionist. "Yes they're back you're in Menopause." I replied "Oh", as I was a little shocked. Not asked if I was OK or offered an appointment, it was hard at first but I got on with it, didn't have HRT.

I struggled with a shoulder injury from 2014 till 2019 when I was offered surgery for a capsule tear. The physio and Accupuncture afterwards came to a stop when Covid lockdown commenced. I caught Covid in November 2020.

I was quite ill, the cough was debilitating, I felt breathless all the time. My pulse oximeter readings were high 80s but falling below 80 my husband took me to Ormskirk Walk in, I was asked to walk a distance then come back in, the oximeter readings were 90 + and I was sent home. Told to come back if they were in the 80s again. They were almost always in the 80s but I could not see the point going back as they made me feel like a liar. I struggled through, tried to go back to work, this eventually led to a crisis as I was afraid to sleep. I was offered talking therapies, some Metazapine, I took myself off them (Felt disassociated). I was seen by Long Covid clinic physio, respiratory from April to June.

Since then I had very little input. I think during the coughing I had done some damage internally, I had continence issues again, weight gain due to inactivity, I have never regained my sense of smell. I lost my toe nails, I don't sleep, I have constant nerve pain. I have post exertional malaise. I am tormented by Phantosmia, convinced I can smell fire or extremely foul smells which actually make me nauseated most of the time. I'm fatigued to the extent it impacted my life and I had to look for alternative part time employment. So I am now in financial hardship.

I have had tests for the Cardio respiratory aspects my Long Covid but they are monitored and needed no action. My issue is, yes, I agree they found nothing but that does not mean I am still not suffering with my symptoms. It's this disregard that is unacceptable, then no follow up.

I was seen in May 2023 for a Gynae procedure, I am still waiting for a follow up appointment, in the meantime I am still suffering. My relationship is under strain and despite doing my best to use Pacing, my quality of life is poor. I feel like suffering Long Covid is not acknowledged or recognised by my GP practice, in fact it is not even on my record.



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