

# HOW DO WE END WOMEN'S HEALTH INEQUALITY?

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WELSH FABIANS

2023

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## Welsh Fabians

The Welsh Fabians are the home of the Fabian Society in Wales.

In July 2021, the Welsh Fabians adopted a formal constitution and elected its first executive committee. Mike Hedges MS is chair and Shahinoor Alom is secretary of the Welsh Fabians.

Our objectives are to:

- Put forward policy options to the Welsh Labour government on a range of issues
- Put on events to debate key issues and come up with new policy solutions
- Raise the profile of the Welsh Fabians amongst the Fabian family
- Increase Fabian Society membership in Wales

Our blog can be found here: [https://medium.com/@mikehedges\\_93307](https://medium.com/@mikehedges_93307)

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# INTRODUCTION

CLLR CATHERINE FOOKES, VICE-CHAIR, WELSH FABIANS

This pamphlet brings together a moving and strong collection of articles around the health inequalities that women of all ages face. From the issues when we start our periods right through to the age we are when they stop and we go through the menopause, our authors show that too often women's health is treated as unimportant. We all have a story to tell of when we were told: "it's in your mind – just a bit of period pain." Or when we have been fobbed off with anti-depressants when we are in fact peri-menopausal.

What this shows is that women's health is underfunded and misunderstood. Recently we have been told by the UK government that cognitive behavioural therapy can help with symptoms of the menopause – tell that to someone who's had countless sleepless nights, chronic anxiety and debilitating hot flushes which are so bad, she has to give up her job. We need more than chats to iron out these inequalities.

From heart disease to endometriosis and from anorexia to postpartum depression, our pamphlet shows that not enough money is put into the research or the treatment of women's health issues.

Our courageous writers put forward some sound solutions – obviously more money for research is part of the answer as is NHS Wales' Co-produced Women's Health Plan, with a new National Strategic Clinical Network especially convened to develop and oversee its implementation. And we need to see dedicated women's health specialists in every GP surgery across Wales.

I want to salute these incredible women campaigners who have contributed – they have banged the drum and raised these issue up the agenda, increasing visibility of these conditions and paving the way for us all to have permission to talk about women's health openly, rather than brushing it under the table.

*Cllr Catherine Fookes is prospective parliamentary candidate for Monmouthshire and previous chief executive of Women's Equality Network (WEN) Wales*

# IN 'THE LAND OF OUR FATHERS', IS WOMEN'S HEALTH A POOR RELATION?

THE FTWWW TEAM

Women, girls, and people assigned female at birth (AFAB) make up around 52% of the population in Wales. Despite this, historically, medicine and healthcare services have not necessarily met their needs, resulting in significant disparities in care.

Undoubtedly, the pandemic has exacerbated the problem: the Royal College of Obstetricians and Gynaecologists last year published a sobering report, 'Left for Too Long' which asked why it is that 'the waiting lists of the only speciality that caters just for women have grown the most of all specialities since the start of the pandemic? Why is there so little discussion or recognition of the impact on women's lives of waiting for gynaecological care and treatment? And how much has the perception of many of these conditions as 'benign'...played into the lack of priority they have long been given?'

Certainly, where gynaecology is concerned, it seems very much as though women's health is a 'poor relation', not just in Wales but across the UK. The question is why — and what can be done about it?

It's important to note that women's health isn't solely comprised of gynaecological matters — but the issues surrounding care for related conditions are a pretty reliable indication of wider problems. The inequalities revealed when scrutinising the provision of gynaecological services are replicated in the care of diseases which impact both men and women, with women experiencing comparatively poor outcomes.

Data from the Office of National Statistics (ONS) finds that women can expect to live fewer years 'disability-free' than men, with women being far more likely to experience chronic illness and its associated impacts on wellbeing and financial security than their male counterparts.<sup>2</sup>

Autoimmune conditions like lupus and inflammatory arthritis, connective tissue disorders like Ehlers-Danlos Syndrome, conditions causing pain and fatigue like fibromyalgia or ME — even long Covid — all of these affect women in far greater numbers than they do men, and all of them seem to suffer from the same lack of investment in research, treatment, and specialist care. It isn't just women therefore who are victims of a widespread failure to prioritise 'women's health'.

The Welsh Government has pledged to be a feminist government and, in 2019, undertook a Gender Equality Review which saw health as a top priority for women across Wales. However, somewhat incongruously, its existing long-term plan for health and social care, 'A Healthier Wales' does not explicitly mention women's health<sup>3</sup>. This isn't an anomaly in policy-making — indeed, Wales is not an exception but merely part of a global cultural landscape which has historically tended to marginalise our needs. Women's exclusion from health service design is encapsulated in the failure to routinely include us in clinical trials, a situation not remedied until the 1990s — even now, there are often assumptions that the male experience is 'typical' so what works for men must also work for women. In her text, 'Invisible Women'<sup>4</sup>, Caroline Criado-Perez evidenced numerous accounts of where this approach doesn't just inconvenience but actually causes harm to women, healthcare being perhaps the most glaring example.

Diagnostic criteria and treatment for conditions that affect both sexes are often based on the male model, resulting in women's symptoms being overlooked or dismissed. An app called 'GP at Hand', designed to use artificial intelligence (AI) to identify health problems, was found to misinform female users that their symptoms of sudden onset chest pain and nausea were 'probably a panic attack' whilst a male patient with the same symptoms was advised to go to A&E for suspected heart attack<sup>5</sup>. The British Heart Foundation's report, 'Bias and Biology' could not be clearer in its summation: 'Over a 10-year period more than 8,200 women died needlessly following a heart attack. They could have been saved if they had received the same quality of care as men'<sup>6</sup>.

When it comes to pain, including both treatment of post-operative pain and in emergency settings, research shows that women wait longer than men for pain relief, and are more likely to be given sedatives instead. At the same

time, data reveals a longer time from the onset of symptoms to diagnosis in female patients in 6 out of 11 types of cancer, with women having to visit their GP more often than men to get a diagnosis. In 2020, the UK Independent Medicines and Medical Devices Safety Review, led by Baroness Julia Cumberlege, criticised a culture in healthcare which sees female patients suffering as a result of a 'widespread and wholly unacceptable labelling of so many symptoms as "normal" and attributable to "women's problems"<sup>7</sup>.

In response to this wealth of evidence, Scotland and England set about developing women's health strategies whilst, in Wales, there was initially a reluctance, largely due to the expectation that 'A Healthier Wales', the Welsh Government's flagship health strategy, would be sufficient. However, as organisations like FTWW made clear, unless efforts were made to ameliorate underlying historical and cultural inequalities, the document's recommendations would remain aspirational yet unachievable for many marginalised groups — including women.

Not wishing to see Wales's citizens left behind, FTWW's solution was to work with the British Heart Foundation Cymru in forming a Women's Health Wales Coalition. Made up of third-sector organisations, Royal Colleges, academics, clinicians, and patients, the aim would be to amass evidence of the need for a holistic, life-course approach to women's physical and mental health. The Coalition's report, 'Women's Health Wales: A Quality Statement for the Health of Women, Girls, and those Assigned Female at Birth'<sup>8</sup> was published on May 28th 2022, International Day of Action for Women's Health. It garnered a huge amount of attention, with BBC Wales covering its launch — and content — in depth.

Persuaded by the data, last year, Eluned Morgan, Wales's Minister for Health and Social Care, announced her commitment to a 10-year NHS Wales Women's Health Plan, with a new National Strategic Clinical Network especially convened to develop and oversee its implementation. Excitingly, it was also confirmed that the coalition — and patients — would be involved in its co-production. This is vital, as NHS Wales's own recent survey of public and patients' views about women's health needs confirmed. Attracting almost 4000 responses, top of the list of priorities was 'having our voices heard'<sup>9</sup>.

Clearly, women are no longer content with being a 'poor relation' when it comes to their health. We now look forward to working collaboratively with policy-makers and healthcare providers to create a Wales which is healthier and more equitable — for everyone, women included.

*FTWW (Fair Treatment for the Women of Wales) is a pan-Wales patient-led charity and disabled people's organisation, dedicated to addressing female health inequality*

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- 1 <https://rcog.shorthandstories.com/lefttoolong/>
  - 2 <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/disabilitybyagesexanddeprivationenglandandwales/census2021>
  - 3 <https://www.gov.wales/healthier-wales-long-term-plan-health-and-social-care>
  - 4 <https://carolinecriadoperez.com/book/invisible-women/>
  - 5 <https://www.thetimes.co.uk/article/its-hysteria-not-a-heart-attack-gp-app-tells-women-gm2vxbrqk>
  - 6 <https://www.bhf.org.uk/-/media/files/heart-matters/bias-and-biology-briefing.pdf>
  - 7 <https://www.immdsreview.org.uk/Report.html>
  - 8 <https://www.ftww.org.uk/2021/wp-content/uploads/2022/05/Womens-Health-Wales-Quality-Statement-English-FINAL.pdf>
  - 9 <https://executive.nhs.wales/networks/implementation-groups/womens-health/womens-health-documents/womens-health-in-wales/>

# BIAS AND BIOLOGY: THE HEART ATTACK GENDER GAP

GEMMA ROBERTS LLB, LLM

The British Heart Foundation (BHF) estimates that at least 100,000 women are living with heart diseases in Wales.<sup>1</sup> The most common of these is coronary heart disease with around 45,000 women in Wales living with this condition. Wales has the second highest coronary heart disease female death rate of the UK's four nations<sup>2</sup> with around 1,300 women dying every year — that is twice as many deaths as breast cancer.

The Welsh Government has published a women's health quality statement which specifically references women's heart health, which is a fantastic step by the Minister for Health. It is now for the NHS to take action to tackle the unconscious biases and disadvantages women experience at every stage of their heart disease journey.

Women are:

1. not seen as being at risk of heart attacks.
2. more likely to be misdiagnosed or diagnosed slowly.
3. less likely to receive optimal treatment.
4. more likely to experience difficulties accessing cardiac rehabilitation.

## **1. Women are not seen as being at risk of heart attacks**

There are long-standing societal biases and misunderstandings which assume that women are not at risk of heart attacks. A 2021 BHF Cymru survey of 1000 people in Wales showed that women are not seen as being at risk of heart disease by the Welsh public. 65% of people in Wales are unable to identify heart disease as one of the leading causes of death for women.<sup>3</sup>

Each year, around 1,700 women are admitted to hospitals in Wales due to a heart attack.<sup>4</sup> Yet women are not seen as being at risk of heart attacks, when women do experience the symptoms of a heart attack their symptoms

might not be taken seriously by themselves or those around them. There is a common misconception that women experience 'atypical' symptoms. However, the symptoms of a heart attack can vary from person to person. The most common signs of a heart attack are:

- central chest pain or discomfort in your chest that suddenly occurs and does not go away
- pressure, tightness, or a squeezing sensation in your chest
- pain, which radiates down your left arm, both arms or to your neck, jaw, back or stomach
- feeling sick, sweaty, light-headed, or short of breath

Anyone experiencing any of these symptoms must seek immediate medical attention. A heart attack is a life-threatening medical emergency. The sooner a person experiencing a heart attack is given medical attention, the better their chances of a full recovery.

Risk factors for heart disease, like atrial fibrillation, high blood pressure, diabetes, and high cholesterol can affect anyone. However, there are also female-specific risk factors for heart disease and heart attack.

- High blood pressure is the biggest modifiable risk factor contributing to premature deaths from heart and circulatory diseases in Wales.<sup>5</sup> High blood pressure has been found to be more strongly associated with heart attacks in women than in men likely due to underdiagnosis and undertreatment.<sup>6</sup>
- Diabetes is more strongly associated with heart attacks in women. Having diabetes doubles the chances that a person might develop cardiovascular diseases, including coronary heart disease and heart attack. There is evidence that women who have diabetes are more at risk than men with diabetes. The UK Biobank found that women with diabetes have a 29% higher risk of heart attack associated than men with diabetes<sup>7</sup>.
- Complications during pregnancy can be risk factors for heart disease later in life. Pregnancy requires a 50% increase in cardiac output and so has a profound impact on the cardiovascular system. High blood pressure during pregnancy, gestational diabetes, pre-term delivery, and miscarriage are associated with increased risk of cardiovascular disease later in life.<sup>8,9</sup>

- Women are at an increased risk of heart disease during and after menopause. During menopause, there are alterations in sex hormones and several detrimental changes in cardiometabolic risk factors<sup>10,11</sup> that put women at a higher risk of heart and circulatory diseases during and after menopause (increased chance of hypertension, obesity, diabetes, reduction in vascular health and fat deposition around organs in the abdomen).

## **2. Women are more likely to be diagnosed slowly or misdiagnosed**

Women not being seen as at risk of heart attack can impact whether a woman presenting with heart attack symptoms receives a timely and correct diagnosis. An incorrect initial diagnosis after a heart attack increases the risk of death after 30 days by 70%.<sup>12</sup> Research suggests that women are 50% more likely than men to receive the wrong initial diagnosis for a heart attack.<sup>13</sup>

BHF-funded researchers at the University of Leeds found that women are referred for diagnostic testing much more slowly than men. The study found that women who had a type of heart attack usually caused by a partially blocked artery are 34% less likely than men to receive a coronary angiography imaging test within 72 hours of their hospital admission.<sup>14</sup>

## **3. Women are less likely to receive optimal treatment**

Not receiving optimal treatment can lead to another heart attack and, in some cases, death. A clinical trial undertaken by researchers at the University of Edinburgh on acute coronary syndrome found that even when diagnosis in women is improved, sex inequalities in treatment persist.<sup>15</sup> The study revealed that women who were diagnosed quickly were still around half as likely as men to receive the recommended treatment.

BHF-funded researchers at the University of Leeds estimated that if equity in treatment were achieved, at least 8,243 female deaths over a ten-year period could have been prevented in England and Wales.<sup>16</sup> This disparity in treatment is likely to be because heart attack symptoms in women are seen as less severe and not taken seriously.

Suboptimal treatment also impacts women when visiting their GP. Examining the management of cardiovascular disease, a systematic review and meta-analysis of over two million patients worldwide found that women were significantly less likely to be prescribed statins, aspirin, and medication for high blood pressure.<sup>17</sup>

#### **4. Women are more likely to experience difficulty accessing cardiac rehabilitation**

Cardiac rehabilitation services are an important part of patient recovery and are largely offered to patients who have had a heart attack or heart-related surgery. Rehabilitation has been proven to reduce the chances of further complications after a heart attack, improve quality of life, and improve patient recovery.

However, female participation in cardiac rehabilitation is low. Across the UK, the proportion of women recruited to cardiac rehabilitation programmes from those eligible is lower than expected.<sup>18</sup>

Flexibility in cardiac rehabilitation provision may be key to inclusivity. Person-centred cardiac rehabilitation is important to allow women in Wales to benefit from an approach that incorporates flexibility.

I wholeheartedly applaud the Minister for Health and Social Services, Eluned Morgan, for the zeal with which she has pursued the women's health agenda. It is now time for the NHS Executive to take up the mantle and ensure these inequalities are tackled in practice.

*Gemma Roberts works for the British Heart Foundation but this is written in a personal capacity*

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**1** BHF (2021) estimate based on Welsh Health Survey responses and latest ONS population estimates.

**2** BHF. (2021). Heart and Circulatory Disease Statistics 2021. <https://bit.ly/3mr8ty6>

**3** YouGov Plc. Total sample size was 1007 adults. Fieldwork was undertaken between 10th – 14th June 2021. The survey was carried out online and results have been weighted for the Welsh adult population.

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- 16** Ibid.
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# MENOPAUSE IN 2023: WHAT'S NEXT?

CAROLYN HARRIS MP

The campaign to get menopause on the map has continued to roll on. It has evolved, gained ground, and suffered setbacks but one constant has remained. Menopause, as part of a wider women's health strategy, has been neglected for too long and that needs to change.

Menopause, and its sly younger sister Perimenopause, is the process where we women reach the end of our menstrual cycles. It affects roughly 13 million of us in the UK. The average age we reach menopause is 51 and women can suffer symptoms ranging from hot flushes to brain fog and reduced libido.

Since I first raised this Issue, we have been inspired by Davina McCall's galvanising 'Sex, Myths and the Menopause' documentary, which has seen hundreds of grassroots activists descend on Parliament three times to demand better support for menopausal women, and witnessed the implementation of the government's commitments following my Private Members Bill (PMB) which sought to reduce the cost of Hormone Replacement Therapy (HRT) NHS prescriptions in England and create a UK-wide Menopause Taskforce.

The long-awaited cost reduction for HRT for women in England finally came into force in the form of a pre-payment certificate (PPC) in April 2023. The sluggish reaction of the Government meant that it took 500 days from the commitment being made to its implementation, but the impact it made was clear to see when demand on the day it launched, caused the Government's website to crash.

Thanks to our wonderful Labour government in the Senedd, prescriptions are free in Wales. But for our sisters in England, the new single annual charge of £19.30 per year for all eligible HRT products, has seen the PPC help over 100,000 women to access treatment.

The dithering and delays ahead of the implementation of the PPC coincided with a severe HRT shortage at the beginning of 2022. The primary product affected at the time was Oestrogel, a gel-based treatment that replaces the oestrogen in women's bodies and is used by thousands across the country. But ever since we have been suffering continuously from shortages of a wide range of HRT products. At the time of writing, Utrogestan, the most popular replacement progesterone product, remains in seriously short supply. What has gone from the inconvenience of women being forced to track down their own treatment has now become a public health risk, as if those with wombs continue to take oestrogen without progesterone there is an increased risk of developing endometrial cancer. The Government's lack of urgency in dealing with this shortage, as well as its failure to educate women about the associated risks, is total negligence.

In the face of these challenges, the menopause movement continually rouses itself, and it was a joint frustration at the lack of desire to prioritise this area of women's health, that saw the formation of the Menopause Mandate in April 2022. Uniting experts and activists alongside celebrities like Penny Lancaster and Carol Vorderman, the group has remained steadfast in its demand for greater support for women experiencing the often debilitating impact of menopause and perimenopause. To celebrate the group's first birthday, they launched a menopause helpline offering women struggling with symptoms, access to free 15-minute 1-1 consultations with a menopause specialist.

Going forward, I am ambitious about what more can be done in the menopause arena, not to give women special treatment, but to enable them to continue their lives as normal from the moment their symptoms begin. If a fairy godmother came along and with a swish of her wand resolved the HRT shortage tomorrow, I would still have a list of priorities as long as my arm.

- I want a national formula created that would help tackle the post-code lottery of access to HRT by removing the anomalous geographical disparities we are seeing at present.
- I want to see improved workplace support for all women going through menopause, with employers pledging to make the changes to keep women in the workplace.

- I will continue to push for improved training for medical professionals to ensure that GPs, practice nurses, pharmacists, occupational therapists, and all other clinicians are better resourced and have the confidence to spot the symptoms and know how to treat them.
- And finally, I won't give up until we see testosterone available for women on NHS prescriptions. When women go through menopause, we become deficient in all three hormones — oestrogen, progesterone and testosterone. The fact that, at present, only two are replaced through standard HRT treatments is a real failure in women's healthcare and is something that needs to be addressed as a priority.

Our fight to get women's health, and the menopause specifically, taken seriously by the government is still in its infancy. To me, it is obvious that menopause should be given the respect it deserves within our society. With the proper support, women will be able to remain in work longer, relationships will survive, the NHS will save money and women will be kept out of the criminal justice system. I do not believe there is a single area of social policy that menopause does not touch, and I will not rest until this understanding is ingrained in our society.

*Carolyn Harris is the MP for Swansea East*

# POSTPARTUM PTSD IS A SERIOUS ISSUE

BUFFY WILLIAMS MS

In Wales alone over 9,000 women are suffering, sometimes in silence.

Mothers have kept their symptoms to themselves, so the condition has remained invisible.

Many mothers, unfortunately, are wrongly diagnosed with postpartum depression, when in fact the trauma of a difficult birth or events directly concerning complications after a birth can leave a mother suffering from postpartum PTSD.

This can include flashbacks of traumatic moments throughout labour that have a mother reliving the fear of the trauma, troubling dreams and nightmares, symptoms of anxiety and not wanting to discuss or be reminded of the events surrounding the birth, also feeling isolated and hopeless.

The birth of a child is one of the most intense and emotional experiences in a woman's life, but, sometimes the best-planned births can quickly become an event in which sadly little joy and happiness are felt.

PTSD can have a detrimental effect on the mother and infant bond, causing distress to both mother and child, early intervention is vital, and we are so lucky that the dedicated midwives and health professionals who are involved in the care of an expectant, or new mother are key for this early diagnosis to take place.

One study showed that 45% of women experienced traumatic childbirth and up to 4.6% of women developed PTSD. There are many reasons for a traumatic childbirth, an emergency C-section, intervention during labour, prolonged labour and injuries suffered during birth are just a few of the many reasons this can occur.

My own personal experience was not a traumatic birth, but the traumatic events that followed directly after and as a direct result of the birth. Those events have, and still do impact my everyday life.

I was told repeatedly by midwives and consultants how lucky I was, lucky to have survived and lucky to have had a quick-thinking midwife. Lucky was a word I became used to hearing, over the days weeks and months following the birth of my daughter.

But lucky was the last thing I was feeling. Frightened, traumatised, confused, alone and anxious these were words more fitting to my mindset. In some ways, I suppose I was lucky, I had a team of dedicated midwives who soon became friends and consultants who were caring and understanding. The care I received at the hospital and when I eventually returned home, was nothing short of outstanding.

However, how many new mothers and mothers-to-be will not be lucky?

How many mothers and lone mothers are suffering in silence?

How many husbands, partners, families and friends are trying to support and care for a mother who is traumatised?

Sometimes the birth partner who witnesses the upsetting experience also takes their own measure of distress and anxiety away from the birth. Who is there to support them?

There are many groups and organisations available to support mothers through this very difficult time, but, when you leave the care of the medical professionals, and you are back in the family unit, you begin to worry that you are a failure, worry that you are letting people down. You feel that you can't ask for help without being negatively judged and you start to feel that no matter where you turn, no one really understands.

How many mothers right now are feeling this way? How many mothers and families are being left to struggle alone? How many children will feel this negative impact, or grow up with strained relationships within the family unit?

Each local health board across Wales offers varying levels of support for mothers and families who are in need of mental health support. Access to these services requires referral through GP or health visitors.

Some mothers are unfortunately wrongly diagnosed with post-natal depression. We need to make sure that our GPs, midwives and health visitors are supplied with the tools and training they need to best care for those mothers who are most vulnerable at a time in their lives that they should feel safe, content and cared for.

With that said I welcome the new mother and baby unit in Swansea Bay. This is a step in the right direction when it comes to the health and well-being of mothers pre and post birth. Until now mothers who have needed serious mental health care were admitted to acute mental health facilities without their babies or would need to travel to a specialist unit outside of Wales. We must do more to combat the stigma of postnatal depression and peripartum PTSD, we must ensure mothers have confidence to confide in our fantastic health care professionals. I believe that the mother and baby unit in Swansea Bay does this and should be replicated across all 7 Welsh health boards.

I want to pay tribute to all maternity staff in Wales. I know the team that cared for me went above and beyond the call of duty.

Whilst we celebrate progress in specialist care in perinatal mental health it is vital, that we do more. It is vital we listen better and it is vital that we all work to remove all stigma surrounding any forms of mental health.

I hope mothers who suffer from any form of PTSD take strength in the knowledge that they are not alone. Please reach out, and ask for help.

*Buffy Williams is the Labour MS for Rhondda*

# ENDOMETRIOSIS: A PROBLEM SHARED IS A PROBLEM HALVED? WE HOPE SO...

THE FTWW TEAM

Since its inception nine years ago, in 2014, FTWW has been campaigning for better endometriosis care. Our very name 'Fair Treatment for the Women of Wales' was originally derived from our founder's challenges in getting both a timely diagnosis of the condition and then, optimal treatment for it – something that wasn't (and still isn't) readily available to patients. This, for a condition that affects one in 10 females – the same prevalence as diabetes or asthma – equating to about 150,000 patients in Wales.

Given the numbers affected, you might be surprised to learn that it takes, on average, around 9 years to get a diagnosis in Wales and even begin the journey to gold-standard treatment (currently excision surgery, where patches of disease are cut out). But that's the reality, compounded by the fact that waiting lists to see a gynaecologist are amongst the longest for any speciality. This was only made worse by the pandemic, which saw operations for 'benign' gynaecological conditions largely cancelled across the UK. Patients tell us every day that they are on waiting lists of two to three years – or even longer if affected by the most severe form of endometriosis, which requires highly specialised and multi-disciplinary care. This type of offer is only available in certain areas of Wales – and if you're unfortunate enough not to live nearby, you may well be denied treatment altogether.

There are some key reasons for this sorry state of affairs – and it would be unfair to say that they only impact patients in Wales. In fact, much of the problem is historical and cultural in origin and extends far beyond our part of the world.

Firstly, many of us are led to believe from childhood that painful periods are 'normal', something to be tolerated, in silence – because periods are embarrassing, and monthly episodes of heavy, painful bleeding are not a 'nice' topic of conversation. And, anyway, 'all girls have periods, and we all just take a paracetamol and wear extra wedges of toilet roll when leaking through our tampons or pads, right? Our mums, our grans – they all "just got on with it", and so must we! In fact, painful periods are often one of the first signs of endometriosis so ignoring the problem and not seeking help can contribute to the long diagnostic delay.

If and when we do seek advice from friends, family, teachers, employers, and healthcare professionals, as you'd expect in a world where period pain is normalised, the significance of the issue can continue to be missed or underplayed. Women tell us that they start to doubt themselves and that frequently seeking support and being dismissed is upsetting, frustrating, stressful, and even traumatic. As the years tick by, the condition progresses and symptoms worsen – for some, the impact on their education, their career, and their relationships, is huge.

Secondly, as you'd expect from a society which doesn't really take period pain seriously, there is a commensurate lack of investment in clinical research, treatment options, or healthcare services. When it comes to research, USA data from 2022 suggest that endometriosis attracts the equivalent of £1.50 per head of the population affected, compared to about £25 per female living with diabetes, a difference of some 1500%. Perhaps this is because endometriosis is considered a 'benign' condition – benign in healthcare-speak meaning non-cancerous, but in everyday parlance suggesting 'not serious', 'not important', even 'friendly', an attitude which has undoubtedly influenced the narrative around much of gynaecology and 'women's health' in general.

The truth is that endometriosis is a progressive condition which has been found throughout the body and, in some patients, is capable of causing organ dysfunction, chronic pain, fatigue, and infertility. Even amongst FTWW's relatively small online community, we have heard from those who have had to have stoma bags fitted, who have lost kidney function, and who, having tried and failed to conceive, have ended up in surgical menopause with all of their reproductive organs removed – and are still

having symptoms of endometriosis! Let's be clear: this is not a 'friendly' disease.

So, what's happening in Wales to remedy the situation? Well, on the back of FTWW's campaigning, a Task and Finish Group was established by the Welsh Government in 2017 to look at the issues in more detail and make recommendations to improve care. Its work concluded in 2018 – and, just as actions were being pondered, the pandemic hit, causing everything to come to an abrupt halt. Nonetheless, the then Health Minister, Vaughan Gething MS, did allocate funding to a Women's Health Implementation Group', or 'WHIG', which was able to make a start on some really positive developments.

One of these was the website [www.endometriosis.cymru](http://www.endometriosis.cymru) which FTWW members were delighted to co-produce with Cardiff University and NHS Wales. Aimed at providing those who suspect or have a confirmed diagnosis of endometriosis with further information and support, it is in the process of being refreshed as we speak. Amongst the resources on offer, it will include a digitised symptom reporting tool to help patients and their healthcare providers have better, more informed conversations about the condition and, hopefully, go some way to reducing that long diagnostic delay.

In addition, the WHIG also provided funds to each of the seven health boards in Wales, enabling them to employ an endometriosis nurse tasked with supporting patients along the arduous pathway between the GP and secondary care, most particularly the gynaecology department. Of course, with a condition as common as endometriosis, one nurse per health board can really only start to scratch the surface of demand. Not only that, there are currently significant variations across Wales on how and where to access them. We look forward to a future where far more are recruited and trained to provide this invaluable service, making it readily available for every patient who needs it.

Indeed, 'access' is perhaps key to improving the care endometriosis patients receive. We believe that no matter where in Wales they live, they should be able to access specialist care when needed. This is proving a more intractable problem but, as the Welsh Government and NHS Wales highlight

the need for collaboration between health boards, and a new National Gynaecology Network starts its deliberations, we remain hopeful that it is one that can be resolved. Until it is, the campaigning continues, and the calls of women across Wales grow ever louder.

*FTWW (Fair Treatment for the Women of Wales) is a pan-Wales patient-led charity and disabled people's organisation, dedicated to addressing female health inequality*

# MENTAL HEALTH AND ANOREXIA IN YOUNG PEOPLE

SARAH MURPHY MS

Child and adolescent mental health is one of the key issues that young people raise with me across Bridgend and Porthcawl. In Bridgend, it was great to host our young person's fair on this very topic with Bridgend Youth Council, where schools, pupils and local support groups came together to discuss how we can make mental health provision better for young people in our community. Because, as with a lot of issues, or all issues related to young people, there are often very well-meaning adults who assume what is best, and this shouldn't be the case. Any decisions that impact young people should at least have the consultation and engagement to ensure that we provide support that will make a difference. I know that our Deputy Minister is absolutely committed to this. I also want to add that one of our Youth Parliament Members from Bridgend, Ollie Mallin, who represents the Carers Trust Wales, also says that people's voices and opinions sometimes are overlooked and undervalued in decision-making, so we do want to make sure that that is always a priority.

I believe it is worth also remembering the integral role that I think young people have played in bringing the conversation around depression and anxiety into our daily lives. We owe much of the work that has been done to break down barriers and the shame of talking about mental health to young people across our communities, and I know this is a priority for our Youth Parliament Member for Bridgend, Ewan Bodilly, who said that, since the pandemic, it has been easy for young people to feel alienated, and it is only through engaging with young people that things will improve. And at the mental health fair, our youth mayor, Xander Payne, said young people have been calling for mental health to be a priority for too long, but the pandemic has shown how important it is that we make sure services are available and mental health is a priority, going forward.

I am thankful to the Welsh Government for their commitment to prioritising mental health for young people through schools with the whole-school approach. There are already schools across my constituency doing this work, with Porthcawl Comprehensive School working with local mental health support groups to destigmatise reaching out and ensuring that all young people know where to turn if they need to. But this should be standardised, and every child and young person should know where to reach out to. Every child should be given the tools to have access to support when and if they need it, for whatever the circumstance is.

I want to say this in support of the call for an eating disorder unit in Wales, preferably a residential eating disorder unit. I had anorexia nervosa when I was 14. It was absolutely terrifying for me and my family, and for my friends and my teachers, and I actually had a chat with my mum about it a couple of months ago when we had the debate on eating disorders because I wanted to speak on it. My mum told me something that she'd never told me before, which was that my paediatric consultant at the time wrote to my counsellor, and didn't even tell my parents that I was two days away from being admitted to the adult psychiatric ward at East Glamorgan Hospital when I was 14. They would have locked me up in an adult psychiatric ward at East Glamorgan Hospital. I would never have come out. So, the only other option at the time was a residential unit, which was in Bristol, and it was full, and my parents were just so scared. I think, to be honest, I was so unwell I don't even think I was scared anymore; I didn't know what was going on.

I did recover, and that is very rare. If you look at the statistics, it's very rare to recover from this but I did. And I can't even really tell you how I did, even now. That was 20 years ago, and we still don't have a unit in Wales. In my community of Bridgend, we do have Mental Health Matters Wales, and a couple of years ago I met Michaela there, and she had an eating disorder group where people who are suffering with it, but also their families, can come together to get support. I'd never really talked about this, and I went in and it all just came out, and we laughed, which I know sounds really strange, but there are just things that are sometimes bizarre, especially some of the things you do when you're going through this. She made me feel so cared for. I just thought to myself, 'God, I wish I'd had you when I was that age. I wish I'd had you, I wish my parents had had you at that age.'

We need a residential eating disorder unit in Wales so that people don't have to move away from their homes.

Finally, we need to say to all young people out there, that you are not alone, there is nothing wrong with you, there is help available, and you can get through this.

*Sarah Murphy is the Senedd member for Bridgend*

# WOMEN'S HEALTH PREMENSTRUAL DYSPHORIC DISORDER

BUFFY WILLIAMS MS

The founder of our national health service was Welsh. We have over 105,000 NHS staff, with over 70 per cent of them women. We have free prescriptions, unlike over the border, but what we don't have is a level playing field. We've heard time and time again, read in very many challenging reports, and some of us have experienced first-hand, the impact of women's health inequalities in Wales. NHS Wales states that although women and girls make up over half of the Welsh population, women's health and well-being are often undervalued and under-resourced, and there is a need to reduce health inequalities, improve quality of service, and improve health outcomes for women in Wales.

We know from the quality statement of women and girls' health that there are 29 health conditions where there is gender inequality, from asthma to dementia, heart disease and stroke, to gynaecological disorders and osteoporosis to mental well-being, anxiety, and depression. But there's also an inequality deep-rooted in our culture, passed from generation to generation, that some conditions experienced by women are viewed as normal, or that it must just be in your head. Women in Wales have heard this for years; sometimes from other women, who've been told it enough that they start to believe it themselves, leading to a multitude of problems later in life.

I wrote previously about postpartum PTSD, an anxiety disorder that affects women, and is very difficult to diagnose, and though we have the state-of-the-art mother and baby unit in Swansea Bay and the amazing charities who provide support like Mothers Matter in Rhondda, there is really very little clinical long-term support available.

I want to highlight another women's health condition. Premenstrual dysphoric disorder — PMDD. It is another condition that affects women

and is very difficult to diagnose, and though awareness and support have grown, it's still nowhere near the level that's needed to reach women who are suffering.

You'd be hard-pressed to find a woman or girl in Wales who hasn't experienced cramps, mood swings, anxiety, irritability, bloating, breast tenderness, changes in appetite or headaches over the days leading to their period: all symptoms of premenstrual syndrome that affect women and girls Wales-wide, a well-known and well-documented condition with a number of treatments available. But there are women and girls who suffer a separate condition: PMDD.

Due to unexplained heightened sensitivity to a spike in hormones, women and girls with PMDD can suffer for weeks, not just days, before their period. They experience symptoms of PMS, but far more severe, as well as additional symptoms of depression or hopelessness, anger or suicidal feelings. Physical symptoms can be debilitating, leading to being bed-bound; women and girls end up missing work or school, and missing important life events for family and friends. Mentally, symptoms will lead to major breakdown over casual events, scenarios or comments that would be seen as ordinary on any other day. These symptoms can be felt for easily over 26 weeks of the year. They will play out on a continuous loop every month, like a tidal wave of torment that simply cannot be stopped.

The consequences on work and school life or relationships and on social life are catastrophic. When the symptoms stop, the problems caused as a result — fights with friends or family, problems at school or work — don't, only adding to the mental health worries. Through no fault of their own, women and girls are often suffering in silence with PMDD. It's a fact that some women just put up with what they're going through without seeking medical intervention, because they should be having a period and periods should be difficult.

I ran a survey for women in Rhondda and I'd like to thank them all for taking part. Ninety-nine per cent of them reported that their period, and the time leading to their period, impacts negatively on their mental health and some have sought medical treatment. I was alarmed to read the sheer number of responses that went into great detail about the difficulties of accessing

healthcare. There's a clear picture emerging that women don't feel listened to, some saying they feel as though they've been fobbed off; others that they felt their healthcare professional wasn't bothered, and a handful who said they felt they were wasting their healthcare professional's time. More alarmingly than this, almost a third of women stated they were put off from seeking medical support as a result of hearing other women's and girls' experiences.

There's a chronic lack of understanding among healthcare professionals in Wales, leading to misdiagnosis and wrong treatments for women suffering from PMDD. The NHS website states very little about PMDD, including the condition as an addition to PMS. Some treatments for PMS do not make a difference to women who suffer PMDD. Young women are told the only alternative is to have hysterectomies. We need to ensure there's a very clear difference — if we don't, women with PMDD will continue to feel lonely, isolated, angry and suicidal. Imagine how awful it must be trying to explain to family and friends how you feel without a diagnosis; trying to explain to work colleagues or managers about your symptoms without a diagnosis.

This must change. 'After suffering years of physical symptoms, including bloating, headaches, mastitis, fatigue and joint pain, trying every remedy that the GP recommended, including the pill, the Depo injection, and even the coil; being told that "it's what women go through", being told I had PMS, and, "had I tried running?" I gave up asking for help. I gave up trying to find answers. I would spend one week of every month living and the other three just existing — getting on with it as most women do. It wasn't until I had my youngest daughter and spent a long period of time being cared for by health professionals who specialise in women's health that I learned of PMDD. For months after having my daughter, I knew something was very wrong. My symptoms worsened. I was suffering so badly; that I didn't want to leave the house. I had mood swings, I was irritable, and I felt lost. My periods were no less than horrific. I was suffering after a traumatic birth and I had all the symptoms of PMDD. I was desperate. Speaking with my consultant, I explained the years of not really understanding what was happening to me. My life was on hold. As a last resort, I was left with no alternative but to undergo a hysterectomy at the age of at the age of 34. This was one of the most difficult decisions I have ever had to make. All the pros and cons were explained to me in detail, but for me, there was only

one choice. The way I explain my hysterectomy to others is that before my surgery I had horrific months of pain. After my surgery, my life completely changed — though I understand that this is not an option for all women and girls.

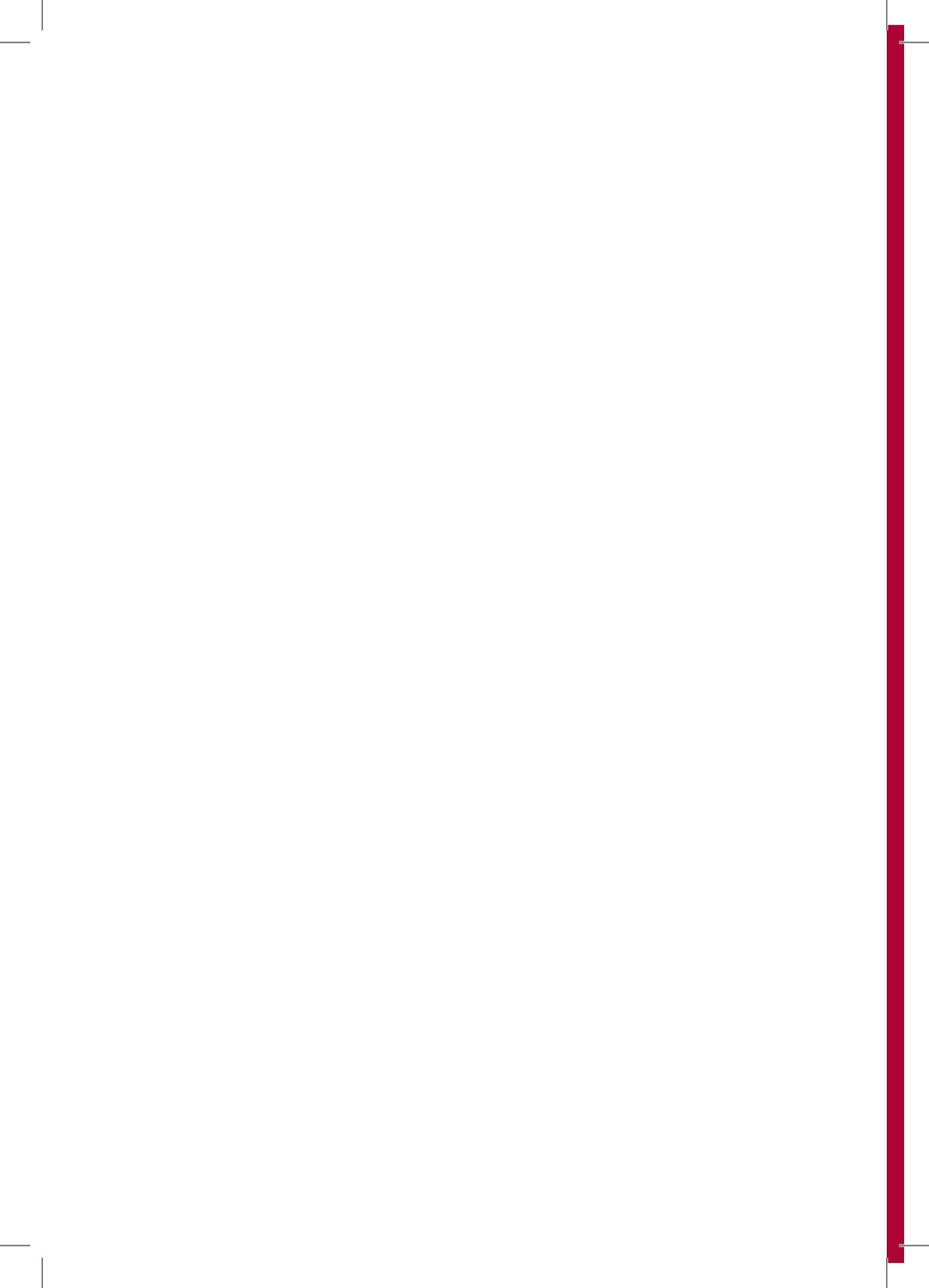
Due to very little research, it's very difficult for women and girls to find information regarding PMDD. It was only less than five years ago that the World Health Organization added PMDD to the ICD-11, helping validate the condition as a legitimate health diagnosis. If it weren't for the charity, IAPMD, we would still be in the dark when it comes to PMDD. Thanks to IAPMD, there is a whole host of information available to women and girls who think they may be suffering from PMDD, from symptoms, and practical steps towards diagnosis, right through to potential treatments and support groups.

On behalf of women and girls who suffer from PMDD, I'd like the Minister to: formally acknowledge that PMDD is a health condition in its own right and ensure that in Wales it's treated that way. We can take the first step very quickly by creating an individual web page on the NHS website for the condition, not just a couple of sentences tagged on at the end of the PMS webpage. I'd like the minister to help women and girls who may be suffering from PMDD to recognise the symptoms, and help validate the condition. We need to end the additional anxiety and upset that comes with facing day-to-day events. A positive long-term action to take would be to run an awareness campaign, encompassing the public, private and third sector, to reach women in schools, workplaces and community groups Wales-wide. This could incorporate a review of whether PMDD is included in enough detail when discussing the reproductive system in schools; informing women and girls how and what to prepare prior to an appointment for a diagnosis; informing sufferers, families and friends on how to help them cope; and promote the recently announced standard on menstrual health and menopause in the workplace.

Off the back of coverage in a popular soap opera recently, I can't think of a better time to kick-start this campaign. Given the strides made in very recent years, I'd like the Minister to hold meaningful discussions with the charity IAPMD, in partnership with primary and secondary care providers, to ensure that our caregivers are fully equipped with the very latest knowledge of

PMDD, ensuring that if and when women and girls present to them, the best possible care and treatment is provided. Last but not least, I'd like the minister to review what research is currently taking place in Wales into PMDD, with a view to in the very near future to working with research partners and fund research of PMDD in Wales. There is currently no blood test to diagnose PMDD. Let's ensure we're at the forefront of this research in Wales. We have an amazing opportunity in front of us to be a nation that leads on women's and girls' health. PMDD must be part of this in its own right to save lives.

*Buffy Williams is the Senedd member for Rhondda*





## **HOW WE DO WE END WOMEN'S HEALTH INEQUALITY?**

Welsh Fabians

Too often women's health is treated as unimportant. This pamphlet brings together a collection of articles around the health inequalities that women of all ages face.

Edited by and introduction by  
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