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FTWW MANIFESTO

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FAIR TREATMENT FOR
THE WOMEN OF WALES

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FTWW Manifesto for 2021

Make Women's Health a Priority for Wales

Women make up some 52% of the population in Wales and are more likely than men to be primary care-givers for younger and older generations (1) whilst also making up almost 50% of the UK workforce, with rates of women in full-time employment rising faster than that of men (2).

Given these significant responsibilities, women's health is fundamental to the well-being of Wales as a nation and yet, historically, it has been neglected: women's health – including maternity provision – was not even mentioned in Welsh Government's existing long-term plan for health and social services, 'A Healthier Wales' (3) . This needs to change.

Given the significant disease burden of women's health conditions – not least endometriosis, which costs the UK economy £8.2bn annually (4) and menopause which will affect 52% of the population at some point in time, FTWW would call upon any incoming administration to both prioritise and incentivise the effective management of women's health.

In primary care, women's health should be included within dedicated funding streams for Enhanced Services which are, in essence, 'essential or additional services delivered to a higher specification...designed around the needs of the local population' (5) in the same way as diabetes. This sees practices delivering consistent, high quality services integrated across primary, secondary and tertiary care, including pan-Wales access to advanced skills nurses.

FTWW RECOMMENDS 5 KEY AREAS FOR THE CONSIDERATION OF POLITICAL PARTIES AS WE MOVE INTO A NEW ERA OF WELSH POLITICS

1) A Bespoke Women's Health Strategy for Wales

This should comprise short, medium, and long-term plans and deliverables, co-produced by organisations like FTWW, and be a core part of all health boards' strategic planning. Implementation should be overseen and evaluated by Welsh Government, in partnership with third sector, the Royal College of Obstetricians and Gynaecologists, and other clinical bodies where appropriate.

It's important to appreciate the need to move away from considering women's health only through the prism of maternity. Whilst a bespoke strategy for Wales would absolutely include this key part of many women's lives, we ask that the opportunity be taken to see and treat women's health holistically, with needs that are separate and distinct from obstetrics.

Over recent times, evidence has emerged from across the UK showing that women's health needs to be taken more seriously, not least in terms of research, into health conditions and treatments, which is inclusive of females. Clinical studies have historically excluded females because of the perceived complications and expense associated with adjusting for hormone fluctuations. Not only has this affected the range and efficacy of medical treatments offered for a significant number of diseases, it has resulted in conditions predominantly affecting women being neglected, and diagnostic models being based on male presentation (6).

The Cumberlege Report, '*First Do No Harm*' (7) is just one of several accounts which describe how women's self-reporting of both symptoms and associated healthcare-related experiences have been systematically dismissed or underplayed, leading to continued misdiagnoses and poorer outcomes. A bespoke women's health strategy, co-produced by women themselves, one which doesn't just focus on obstetric and gynaecological conditions but looks at women's health experiences more generally, would see the needs of 52% of the population properly and rightfully prioritised, ensuring a cradle to grave approach.

A Women's Health Strategy for Wales should incorporate:

i) A focus on life-long women's health

In line with Welsh Government's commitment to the Prudent Healthcare Principles of prevention and early intervention, a Women's Health Strategy for Wales should include regular health checks and data collection / analysis to identify any existing concerns, speed-up diagnoses and access to appropriate interventions, and pre-empt health issues that may arise later in life.

Of key concern is the need to identify, monitor, and support women at risk of cardiovascular disease. The British Heart Foundation's research (8) evidences how women's symptoms are often dismissed due to lack of awareness on the part of both women themselves and healthcare professionals, and a tendency to consider heart problems as 'a male issue'. The result is that women's outcomes are poorer and costs to health services higher. Women at particularly high risk can be identified much earlier, including those who develop pre-eclampsia during pregnancy and those who have auto-immune illness like systemic lupus erythematosus (SLE).

ii) A consistent, pan-Wales approach

A Women's Health Strategy for Wales should be applicable across all health boards and ensure easy access to specialist services wherever they may be located, whether this be in a specific health board or across the border in England.

Historically, the lack of awareness and investment in women's health conditions has seen a correlating lack of specialist services and, consequently, difficulties accessing them for patients 'out of area'. A Women's Health Strategy for Wales would see joined-up, pan-Wales planning and pathways, clearly and consistently signposted for patients and their local healthcare providers, whether that be the GP, nurse practitioner, or secondary care consultant.

The Strategy should also facilitate the use of a combination of approaches to care, requiring investment in technology to allow phone and video, alongside in-person appointments, so that women and their healthcare providers can choose the most appropriate methods for the individual's needs, circumstances, and location, thereby overcoming any potential obstacles to care closer to home. Welsh Government should also make electronic health records a reality, so that patients are given the means to manage their own health and healthcare as far as possible.

iii) Investment in research

More research into women's health, including conditions which predominantly affect them, is a matter of urgency and something in which Wales could play a leading role. Existing and ongoing clinical research should be disaggregated by sex, so that there is a clear sense of how emerging interventions and treatments affect females.

Aside from vital research into causation, treatment, and cures, it is also fundamentally important to look at ways to improve women's experiences in healthcare settings more generally. Any research and recommendations of this nature should be co-produced with service-users.

iv) The involvement of Public Health Wales

Public Health Wales already plays a key role in the delivery of screening for women's cancers. However, of equal importance is their role in messaging, awareness and education, all of which would feature in an effective Women's Health Strategy. Public Health Wales's stated aim of 'supporting the development of a sustainable health and care system focused on prevention and early intervention' (9) should include raising the public profile of women's health, such as menstrual health issues and menopause, including symptom awareness and enabling appropriate help-seeking and targeted interventions.

v) Working with Wales's Employers

A Women's Health Strategy for Wales would be a useful lever in improving women's experiences of employment, underpinning women's health and wellbeing policies and practices in the workplace.

According to the Office for National Statistics, in 2020, 75% of women aged between 16 and 64 are in employment in the UK (10). However 20% of those living with endometriosis in Wales report being unable to continue in employment due to symptoms and lack of support (11), whilst the TUC's research showed that 45% of employees going through menopause found their symptoms difficult to deal with (12)

An all-encompassing Women's Health Strategy for Wales would provide advice and information for employers, giving them the means to facilitate more support for their female employees, improving productivity, well-being, and contributing further to the economy of Wales.

vi) Sustainable resourcing of third sector

Wales has a legal mandate for both co-production, and citizen voice and control. The voluntary sector is most often the space in which patients come together and have the support necessary to either advocate for themselves or elicit advocacy on their behalf. Welsh Government recognises that services are more fit-for-purpose and cost-effective if they are co-produced at every level and, most often, it is the voluntary sector providing the means for this to happen.

Furthermore, Wales continues to move towards a system of social prescribing, where the voluntary sector provides support and activities alongside, or even in place of, traditional medical interventions. This provision is vital in supporting women's health and wellbeing, where so often women with chronic illness and / or menstrual health issues feel isolated and marginalised.

To ensure both co-production and social prescribing continue across Wales, at a local and national level, there needs to be a commitment to sustainable funding for the sector providing the mechanism for service-users to engage in the process of co-production, and the social prescribing programmes from which service-users, public sector, and the economy in Wales benefit.

A Women's Health Strategy for Wales should be overseen by Welsh Government, partly through

2) A Long-Term, Sustainable Commitment to the Wales Women's Health Implementation Group (WHIG) & Programme (WHIP)

An incoming Welsh Government should:

- expand the existing remit of the WHIP
- dramatically increase its funding in recognition of the numbers of people for whom services are required
- make the WHIP a long-term part of healthcare delivery in Wales

- ensure the WHIP is staffed sufficiently to enable effective project management for each health condition as it arises / is added to WHIG's remit, and
- commit to ensuring sustainable patient representation and co-production of the services it oversees.

FTWW sees the WHIG's focus as being not just on gynaecological care / services but a range of health conditions which predominantly affect women. There would also be a role for WHIG in making sure that other areas of healthcare, including research and training, are both inclusive of women and improve their experiences in clinical settings.

FTWW's members consider the following health conditions to be priorities, although this should not be seen as an exhaustive list. For each of them, **raising awareness in medical training and the patient community are key** to making improvements:

i) Endometriosis

- Reduce diagnostic delay from an average 9 years in Wales (13) to 2 by 2025
- Ensure each health board works with patients to develop a clear pathway, incorporating specialist endometriosis nurses, pelvic wellbeing services (including pain management and physiotherapy), local endometriosis leads in secondary care, and assured access to tertiary care in a designated centre
- Ensure joined-up care includes fertility and menopause services, where appropriate
- Ensure that extra-pelvic endometriosis is included in guidelines and that there is access to multi-disciplinary teams able to treat it effectively
- Move away from historical and inadequate block funding arrangements for specialist endometriosis services, to the Welsh Health Specialised Services Committee (WHSSC).

ii) Poly-Cystic Ovary Syndrome (PCOS)

- Reduce diagnostic delay
- Ensure each health board works with patients to develop a clear pathway, incorporating access to gynaecology, endocrinology, and fertility services, where appropriate

iii) Pre-Menstrual Dysphoric Disorder (PMDD)

- Reduce diagnostic delay
- Ensure a joined-up multi-disciplinary approach, to include gynaecology, specialist mental health support, and menopause services where appropriate

iv) Miscarriage & Recurrent Miscarriage

- Look to changing the narrative and terminology around miscarriage to 'pregnancy and / or baby loss'
- Ensure pan-Wales access to consistently high-quality maternal and post-partum mental and physical support services
- Ensure women experiencing miscarriage and / or fertility treatments are properly supported in the workplace and have pregnancy-related protections extended to them
- Have health boards commit to treating women going through miscarriage more sensitively, including being seen and treated in physical spaces or clinics separate to maternity and / or labour wards
- Reduce the criteria for recurrent pregnancy loss to 2 losses, in line with European Society of Human Reproduction and Embryology (ESHRE) guidance (14)
- Invest in the development of 2 specialist recurrent pregnancy loss clinics in North and South Wales, ensuring pan-Wales pathways and provision for women across the country

v) Menopause

- Work with Public Health Wales to devise and disseminate a formal letter to women aged 40 or earlier, signalling onset of menopause, symptoms, and useful resources, and signposting to appropriate local services, including healthcare
- Conduct an audit of GP practices in Wales to assess adherence to the National Institute for Health and Care Excellence (NICE) guideline on the management of menopause, to include the prescribing of Hormone Replacement Therapy (HRT) over and above anti-depressants
- Require every health board in Wales to offer a least one dedicated, specialist menopause clinic for its population
- Ensure that clinics incorporate a multi-disciplinary approach for more complex patients and offer DEXA scanning, be consultant and specialist-nurse-led, with British Menopause Society (BMS) and / or Faculty of Sexual and Reproductive Healthcare (FRSH) training, and appear on the BMS's map of recognised menopause specialists
- Recommend that clinics offer self-referral as well as GP triage and referral

vi) Auto-immune Disease

- Recognise that auto-immune conditions have an 80% female prevalence and work to overcome the associated biases that have led to insufficient research and diagnostic delay

- Ensure that cross-border pathways are in place to enable patients to access tertiary specialist centres of excellence
- Require local rheumatology services to elect auto-immune disease leads and ensure appropriate continuing professional development and training to enable local management of patients in partnership with specialist personnel and care-plans
- Recognise the complex and life-long implications of auto-immune disease by making sure patients have regular appointments, reviews, and easy access to multi-disciplinary care

vii) Ehlers Danlos Syndrome (EDS), Hypermobility Spectrum Disorders

- Initiate and oversee a programme of work to overcome the diagnostic delays which disproportionately affect female sufferers (15)
- Ensure that cross-border pathways are in place to enable patients to access tertiary specialist centres of excellence
- Require local rheumatology services to establish EDS leads and ensure appropriate training to enable local management of patients in partnership with specialist personnel and care-plans
- Recognise the complex and life-long implications of EDS by making sure patients have regular appointments, reviews, and easy access to multi-disciplinary care, including specialised physiotherapy where appropriate.

viii) Chronic pain and fibromyalgia

- Initiate research on fibromyalgia, looking at causation and potential treatment, whilst working to challenge the prejudices and negative stereotypes that surround the condition and women's experiences related to it
- Invest in consistent, pan-Wales provision of multi-disciplinary pain management programmes, to include a specific focus on pelvic pain and wellbeing
- Ensure that sufficient and highly trained personnel are in place in every health board to provide specialist pelvic physiotherapy for scar tissue release and hypertonic pelvic floor, sexual and / or organ dysfunction, and psychotherapy / mental health support

ix) Specialist support for Women's Mental health

- Further develop peri-natal mental health provision as a matter of urgency, to include specialist mother-and-baby beds in North and South Wales; extend out-patient peri-natal mental health services beyond 12 months in light of the delay many women experience in being referred into local services; provide additional support for women who have been in care and / or have suffered

early life trauma throughout pregnancy and beyond to improve maternal outcomes

- Invest in sufficient and accessible service provision for the increasing numbers of young women self-harming and / or living with eating disorders. For the latter, in-patient clinics within Wales would ensure care-closer-to-home
- Recognise the impact of delayed diagnosis for autistic girls and women; invest in raising awareness of the different presentation for girls and women, and provide focused mental health interventions to support them during and beyond the diagnostic process
- Invest in increased provision of mental health support for women with secondary breast cancer across Wales
- Make mental health interventions and access to psychological therapy a key part of chronic disease / pain services to better support women in coping with symptoms and treatments, so that they can continue to function at home and in work

A key element of WHIG's remit would be the development of pan-Wales

3) Women's Health Hubs

Women's Health Hubs should exist in every health board and be accessible to all, in line with the Prudent Healthcare Principle of 'Care Closer to Home'. Ideally based in community settings, technology would enable alternative ways of engaging with service-users depending on patient choice and need.

Women's Health Hubs should offer a one-stop-shop for routine gynaecology, including pelvic examinations and ultrasound scanning, sexual health, contraception, screening, and associated services such as pelvic pain management, physiotherapy, mental health, and drop-in Menopause Café-style self-management and support. They should also enable straightforward access to more specialised testing, procedures, and interventions where necessary.

Central to the success of Wales's Women's Health Hubs would be a holistic, multi-disciplinary approach, efficient communication between the various teams and the patient to enable joined-up management of complex care needs, patient access to electronic notes, and a self-referral mechanism which empowers women and enables them to be proactive in the management of their health and healthcare needs...

The effective treatment of which would, in large part, include

4) Training of Healthcare Professionals

FTWW members, and women more generally, have long argued for improvements in the care they receive, not least an increased awareness on the part of healthcare professionals of those health conditions which commonly and / or predominantly affect women, including endometriosis and menopause, for example. Of equal importance, however, is a change in culture which too often sees women reporting feeling dismissed and disempowered.

Existing clinical guidance and NHS Wales strategy focuses upon the benefits of 'shared decision-making' and service-users having 'voice and control', yet women regularly report feeling that they're at the mercy of biases which under-estimate the seriousness of their symptoms and the level of knowledge they have acquired on their condition(s). Partly, this can be attributed to insufficient research and training on women's health conditions, but societal gender stereotyping and the normalisation of gynaecological symptoms also play a key role in making medical appointments often unsatisfactory for women.

To both reduce diagnostic delay and improve women's experiences in clinical settings, an incoming administration in Wales should:

- Ensure that the curricula utilised in Wales for nurse and doctor training are co-produced by patients to include more elements of women's health
- Require initial medical training and continuous professional development to be co-designed and co-delivered by patients, to include lay involvement in assessment and appraisal as a formal requirement in Wales
- Make recognising and challenging unconscious bias an integral element of all healthcare professionals' learning
- Invest in the creation and delivery of bespoke training for advanced skills nurses specialising in women's health, ensuring provision across Wales and in every health board, within primary care and / or women's health hubs
- Ensure the continuing professional development of gynaecologists in Wales to include advanced laparoscopic skills and more specialised knowledge of the endocrine system
- Ensure the continuing professional development of rheumatologists in Wales to include more specialised knowledge of auto-immune disease and hypermobility spectrum disorders like EDS
- Require the upskilling of health visitors to provide better post-natal support, both in terms of physical and mental health

- Invest in the recruitment and training of pelvic physiotherapists able to provide hands-on interventions during / after pregnancy, for pain-management, and post-operatively
- Ensure that all healthcare professionals have access to a regularly maintained database detailing referral pathways and tertiary, specialist services available to patients...

Future generations of whom would be better equipped to overcome societal taboos and myths around gynaecological health by ensuring

5) The Mandatory Inclusion of Menstrual Wellbeing Education on the School Curriculum for Wales

Made compulsory in England from September of this year, the need for all pupils in Wales to receive consistent, evidence-based, high quality menstrual wellbeing education was brought into stark relief by the All-Party Parliamentary Group for Endometriosis report findings, published in October 2020 (16).

The report revealed that Wales has the worst diagnostic delay for endometriosis out of all 4 UK nations: a shocking 9 years. For a condition affecting 1 in 10 females / those assigned female at birth, the symptoms of which commence around the time of onset of periods (12 years) the repercussions on education, attainment, health, fertility, and long-term prospects of such diagnostic delay can be catastrophic.

Endometriosis is not the only menstrual-related condition affecting significant numbers of girls and women, and beset by delays, however. Others would include heavy menstrual bleeding, affecting 1 in 5; Polycystic Ovary Syndrome (PCOS), affecting 1 in 5-10; Pre-Menstrual Dysphoric Disorder (PMDD) affecting 1 in 20, and Premature Ovarian Insufficiency (POI) affecting 1 in 100 before the age of 40 (17).

The reasons for such delays are complex but, for the most part, they can be attributed to societal myths and taboos which normalise symptoms associated with periods, such as pelvic pain and heavy bleeding, whilst also preventing open, accurate discussion where young people learn what is normal and what isn't, and are empowered to seek medical help when appropriate.

FTWW would ask that:

- **Schools throughout Wales are properly resourced to provide consistent, high quality materials and teaching on the topic, thereby avoiding variation and further inequality**
- **Voluntary sector organisations are adequately funded to deliver teacher training, create materials, and provide visiting speakers with lived experience to complement teacher-led lessons**
- **Menstrual Wellbeing Education be formally timetabled within schools' curricula**

The impact of mandatory menstrual wellbeing education is both immediate and long-term: immediate because young people will have the information they need to challenge misconceptions and ask for help; long-term because our future generations of employers, medical professionals, and healthcare workers are in today's classrooms. Teaching menstrual wellbeing now sees women's health properly understood, supported, and treated tomorrow. As such, it is a vital component of any Women's Health Strategy for Wales.

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