



## **Peer-to-Peer Support Programme**

Research undertaken by Public Health Wales shows that adverse childhood experiences are key determinants in the development of long-term health conditions later in life. Partly in response to this data, in 2015, Welsh Government created a ground-breaking piece of legislation, 'The Well-being of Future Generations Act' which aims to improve the environment, experiences, and opportunities of communities now, for the benefit of those coming after. Good health is a fundamental part of that and, with women still being the primary care-givers for the nation's children, ensuring their access to sound health education and best practice is vital if we're to improve the life-chances of future generations, and see Wales lifted out of its current status as one of the poorest countries in Western Europe.

FTWW was created as a result of one Welsh woman's experience of not being able to access gold-standard treatment for endometriosis, a gynaecological condition affecting one in ten of the female population (around 150,000 women) which causes life-impacting pain, organ dysfunction, and fatigue. During the 26-year wait for a diagnosis, and subsequent 2-year battle to access appropriate surgical treatment, it transpired that there were a number of factors contributing to the problems women experienced in accessing care, and that it wasn't limited to endometriosis.

These factors included: taboos around gynaecological health: myths and misconceptions being perpetuated by peers, family, public, and medics alike; gender-prejudiced attitudes experienced in healthcare settings; a system in Wales which prevents patient choice about nature and location of service delivery; a gradual diminishing of voice and control; disempowerment, disengagement, isolation, and worsening mental health.

As a result, a patient-led peer support community was set up online for women the length and breadth of Wales who were living with chronic health conditions, both physical and mental. Originally devised for the sharing of information around treatment and referral pathways for endometriosis, it now embodies a whole host of other conditions affecting women in Wales and for whom the experiences around accessing care are similar.

The online group aims to empower its members with knowledge of symptoms and services, whilst also sharing advice on how to get the best out of appointments, starting with managing anxiety, learning how to voice concerns and challenge their HCPs appropriately, and enabling women to play an active role in the decision-making process so that they can share equally in planning their healthcare.

The creation of such a forum has brought together many hundreds of diverse women across Wales, many of whom are isolated as a result of ill health and ensuing relationship breakdown and poverty. The group has now become a formally constituted third-sector, not-for-profit organisation which works with the NHS in Wales to promote and devise improved services for women (including endometriosis, adenomyosis, pelvic physiotherapy, miscarriage, menopause, Ehlers Danlos Syndrome, and autism, to name but a few), leading education sessions for medics, and advocating for its members at the highest levels. We have recognised both the need for the organisation to be known and utilised more widely, but also that our current provision would benefit by being more consistent and sustainable.

Funds are therefore required to:

1) Co-produce and create more online (and physically available) patient-led, bi-lingual resources on subjects such as techniques to help manage pain / stress / anxiety and promote well-being; questions to ask healthcare providers; how to prepare for surgery and post-op recovery; rights under the Equality Act 2010; how to make a complaint / letter templates, etc. Funds would be needed to cover design and printing costs, and to update the website accordingly.

2) Promote the existing online patient-led peer support group across Wales by lobbying health boards and NHS Direct to ensure FTWW is linked across all public-facing platforms. This would also necessitate networking via attendance of conferences and events where we can set up a stall to impart information, empowering members to apply to be on Boards, and participate in as many local health board forums as possible. In order for members to feel confident and fully-equipped to do this, we need funds to provide adequate bi-lingual resources, coaching for our volunteers, and be able to pay their travel / subsistence costs.

3) Facilitate FTWW in-person peer-support groups across Wales (ideally at least one per health board area). Having trialled one-such in central North Wales for the past 18 months, with meetings every 6 weeks, we have seen just how dynamic, empowering, and supportive this type of provision can be. Not only does it provide both an informal network of women experiencing similar issues, so that sharing of knowledge and advice is enabled, it also creates strong bonds of friendship for those who have been isolated by their ill health and the taboos surrounding it.

Further, the existence of the North Wales group has also proved an incredibly useful forum for inviting health board and similar personnel to come and learn about the experiences of local women. The local in-person group has been instrumental in the development of BCU's 10-year women's services plan, the creation of educational resources for Bangor University's nurse-training programme, as well as contributing to DWP and Welsh Government consultations.

We now need funds to replicate this model across Wales. This requires developing a recruitment and induction, monitoring, and evaluation programme for volunteers and co-producing the necessary resources so that they have the confidence, skills, and knowledge to both set up and promote the existence of a group for their locality, as well as liaise with relevant bodies (health boards / universities / policy-makers / politicians) to ensure their involvement where possible.

Why is this peer-support network an essential part of health improvement strategy across Wales? In essence, it enables girls and women across the region to have voice and control over their health

and lives.

Firstly, it improves understanding of the various conditions with which women are living and facilitates open, accurate discussion about symptoms which are often surrounded by stigma and shrouded in mystery and myth. To that end, it speeds-up help-seeking and aids in making a prompt diagnosis. For many women, it is this delay which can be instrumental in escalating mental health issues and poorer outcomes.

Secondly, it gives women the opportunity to share experiences around self-management, including dealing with symptoms and learning to handle inevitable daily stresses of living with a chronic health condition. Having a knowledgeable and supportive network reduces isolation (which in itself can be as detrimental to health as smoking) and also reduces the number of non-essential visits to healthcare providers.

Thirdly, it empowers women with knowledge around disease presentation, treatments available, referral pathways in place, and how to use this knowledge to assist their doctors in ensuring that the patient receives optimal care for her situation. Getting things right in the first instance means fewer appointments, fewer failed interventions, and more positive outcomes.

Fourthly, it provides a forum where women are able to come together and get involved in healthcare provision at a strategic level. Opportunities to participate in consultations, and have their voices heard as part of campaigns for improved services means that patients who may ordinarily have remained silent – and suffering – can now be pro-active in driving change to how healthcare is delivered, for the benefit of themselves and future generations.