Improve Endometriosis Healthcare in Wales

Y Pwyllgor Deisebau | Chwefror 2022 Petitions Committee | February 2022

Reference: SR22/1851-4

Petition Number: P-06-1242

Petition title: Improve Endometriosis Healthcare in Wales

Text of petition: Endometriosis devastates the lives of women and their families living in Wales with 1 in 10 suffering with the condition. The cause of endometriosis is unknown, there is no cure, the average diagnosis time is currently 8.5 years and there's a 6 year waiting list for treatment on the NHS.

The demonstrable lack of understanding of the condition is detrimentally impacting society at all levels. Funding therefore needs to be prioritised to ensure equality of healthcare in Wales.

More details

A report commissioned by the Welsh Government in 2018 highlighted how big a problem we're facing with resources being wasted and harm currently being caused to individuals suffering with Endometriosis. Despite the findings showing impacts on healthcare, education, economic, financial and social levels within society, most recommendations haven't been adopted, and in many areas things have instead worsened for sufferers of Endometriosis.



1. Background

Endometriosis is a disease where tissue similar to the lining of the uterus grows elsehwere in the body. Endometriosis is a disease affecting 1 in 10 women. Common symptoms include chronic pelvic pain, painful periods, pain during or after sex, painful urination and bowel movements, fatigue and infertility.

There are long waiting times for endometriosis care in Wales. Endometriosis UK say that those needing specialist care, such as complex surgery at an endometriosis specialist centre are in some cases being told they will now wait for several years for that surgery.

Long waits for surgery can have a negative impact on quality of life including ongoing chronic pain and debilitating symptoms that leave some unable to work.

2. Welsh Government action

Following a <u>report</u> by the charity Fair Treatment for the Women in Wales (FTWW) on endometriosis care in Wales, the Chief Executive of NHS Wales established a Task and Finish to review endometriosis services.

The Endometriosis Task and Finish Group submitted its <u>report</u> to the Welsh Government in 2018. It concluded that service provision for women and girls with endometriosis was not meeting their needs, resulting in insufficient access to appropriate care across Wales.

In her letter to the Petitions Committee, the Minister for Health and Social Services, Eluned Morgan MS says "I am aware that, in spite of efforts to change things, there can still be a lack of understanding of endometriosis among some health professionals and that current provision sometimes falls short of what we, and service users, might expect".

Health boards have a responsibility for the delivery of gynaecology services and for the management of endometriosis care in accordance with <u>NICE guidance</u>.

The Minister explains in her letter; "Welsh Government officials wrote to health boards in August 2018 seeking assurance that services were being delivered in line

with the NICE guidance on endometriosis and all health boards confirmed compliance".

The Welsh Government's Women's Health Implementation Group (WHIG) has been allocated £1m a year to support its activities, including working with health boards to improve endometriosis care. The Minister says this includes "the recruitment of a network of specialist endometriosis nurses in each health board to develop national pathways to help to reduce diagnostic times across Wales and again ensure women with the condition are fully supported whilst awaiting or undergoing treatment".

3. Welsh Parliament action

During the Fifth Senedd, endometriosis was <u>debated in the Senedd</u>; led by the then Chair of the Cross Party Group for Women's Health, Jenny Rathbone MS. In his response to the debate (which took place on 14 October 2020), the former Health Minister Vaughan Gethin MS said that "services in Wales were not acceptable" and committed to writing to all health boards to seek assurances that endometriosis care would be prioritised.

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