

P-06-1242 Improve Endometriosis Healthcare in Wales – Correspondence from the petitioner, 28 January 2022

Good Afternoon,

Many thanks for your e-mail and I really appreciate the Petitions Committee taking the time to consider my petition on 7th February.

I have read the attached response from Eluned Morgan MS and this continues to inadequately address the issues that I'm raising.

My thoughts on the attached document are as follows:

- I have previously received similar responses from the Health Minister's office since I first started asking for her help with this issue in July 2021. Unfortunately, the responses continue to provide out-of-date and incorrect information whilst ignoring the questions I've been trying to raise.
- *The questions that I'm looking to raise are as follows:*
 1. *NHS waitlists are currently in excess of 5 years for endometriosis treatment. What element of the £140m pledged by the health minister on 19/08/2021 for tackling NHS waitlist backlogs in Wales will be allocated to help reduce this?*
 2. *Accredited endometriosis specialists have recently been reduced from 3 to 2 for the whole of Wales (rather than being increased to 6 as the Government's 2018 report recommended it should be to ensure Wales are offering the same standard of treatment as the rest of the UK). What are the timescales for increasing the number of endometriosis specialists?*
 3. *As there are currently no endometriosis specialists outside of Cardiff, what plans do the Welsh Government have to ensure equal access to endometriosis healthcare regardless of geographic location within Wales moving forwards? I'm aware that endometriosis nurses have recently been recruited to each of the 7 Health Boards which will of course ensure some degree of equity in terms of that support. However, with sufficiently skilled surgeons and multi-disciplinary teams inaccessible to most patients, how can the nurses alone support the number of patients affected and how can they make referrals if there are no specialist surgeons or centres to take them?*

4. *With UHW currently having the only fully-accredited specialist centre for endometriosis in Wales, are there plans to develop similar facilities in other Health Boards and if so what are the timescales for this? And are there plans to take forward recent recommendations from a third sector coalition for a new NHS Executive who would have sufficient statutory powers to mandate all 7 Health Boards, ensuring they can work together in the best interests of patients (similar to the process with fertility treatment where funds follow the patient due to the involvement of WHSSC) and help end entrenched postcode lotteries in Wales?*

- A Welsh Government Report commissioned in 2018 highlighted how big a problem we're facing and found that a lack of access to appropriate care had resulted in "non-prudent use of resources and waste and harm for individuals and service providers". Despite these findings, the recommendations which would have the biggest impact still haven't been implemented and in many areas the situation has instead worsened. The report also highlights that there are "disparities in care and choice offered to patients living in England compared to those in Wales" as we should have six endometriosis specialists in order to level-up with the current provisions available in the other home nations. Wales's sole endometriosis facility is "inadequately funded" and the current "financial situation is unsustainable", so there is a clear message from the report that additional resources are urgently required to ensure NHS Wales starts meeting NICE quality standards. This information from the 2018 report, as well as my more recent experiences as a patient, contradicts the Health Minister's suggestion that NICE guidance is being complied with. I'd suggest that a lot has happened since 2018 and it may be prudent for the Health Minister to check again with Health Boards, especially considering the situation has deteriorated hugely over the last 4 years.
- It's excellent news that pelvic health co-ordinators and specialist endometriosis nurses have been recruited, however I refer you to question 3 above. I was diagnosed with endometriosis in 2015 and I'm still awaiting an appointment with the Cardiff and Vale endometriosis nurse. Also two of the three surgeries I've had to undergo for endometriosis had to be done privately due to the ever increasing NHS waitlist times (2 years in 2015 and 6 years in 2021). This ongoing increase isn't surprising considering patients only have access to two specialists in Wales, both of whom are based in UHW

Cardiff. Therefore although this recent recruitment in all 7 Health Boards is much needed progress, if the issues relating to all aspects of the patient pathway aren't addressed (such as specialist consultants being recruited) then this alone won't solve the problem and will instead create a bottleneck of patients and further increase waiting list backlogs;

- It hasn't been mentioned in the Health Minister's response (which I'm surprised at), but in October 2020 Jenny Rathbone MS proposed a motion that the Senedd should recognise the devastating impact of endometriosis, acknowledge the diagnostic delay, make menstrual wellbeing education mandatory for all Welsh pupils, and ensure that more endometriosis specialists are trained and accessible to patients across Wales. Despite the motion being unanimously agreed, the position in Wales hasn't improved for the majority of patients and due to this lack of action endometriosis care is now in crisis in Wales. We've lost a specialist and there are no plans to replace him, referrals are being rejected (against NICE guidance), and patients are being forced to take out loans to pay privately for treatment if they're not able to wait up to seven-and-a-half years for the surgery they need. The system was near breaking point before the pandemic, but now it has been completely decimated.
- If the situation is left to deteriorate any further then all patients could be left without access to specialist endometriosis treatment in Wales, unless they have private healthcare. I therefore believe that if the Welsh Government want to fulfil their pledge of being a Feminist Government and meet their responsibilities under the Well-being of Future Generations (Wales) Act 2015, they have to address this issue urgently and give it the full attention and understanding it deserves for the nearly 6,000 people who signed this petition, for the (minimum) 10% of women who suffer with endometriosis and for all the women of Wales who deserve to have healthcare equality.

I really need your help in ensuring the Welsh Government urgently act upon the recommendations and promises that have already been made, especially as the Senedd's Health and Social Care Committee has made 'Women's Health' one of its top priorities for this Senedd term.

Many thanks and best wishes,

Beth Hales

The committee may also find the following links and attached documents useful when considering the petition:

- Link to the Welsh Government Endometriosis Task and Finish Group Report 2018
- <https://gov.wales/sites/default/files/publications/2019-03/endometriosis-care-in-wales-provision-care-pathway-workforce-planning-and-quality-and-outcome-measures.pdf>;
- Link to the Senedd Cymru Member Debate on Endometriosis 14/10/2020
- <https://record.senedd.wales/Motion/7304>;
- Link regarding the recent recommendations for a new NHS Executive
- <https://www.rcplondon.ac.uk/news/rcp-joins-more-20-organisations-call-independent-nhs-wales-executive>
- Link to a Nation Cymru opinion piece which I wrote to provide some further information about endometriosis and the issues patients are currently faced with
- <https://nation.cymru/opinion/not-just-a-bad-period-why-its-past-time-we-improved-endometriosis-healthcare-in-wales/>
- Correspondence to Jane Hutt MS in her capacity of minister for Social Justice;
- Correspondence to Jenny Rathbone MS who is supportive of the petition and who will be accepting a 'hand-in' of the petition outside the Senedd on Wednesday 2nd February at 1pm;
- Timeline of events over the last 4 years regarding the provision of endometriosis healthcare in Wales to provide background on the on-going issue;
- List of organisations who are supportive of the petition and the urgent call for action.