

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Cefnogi pobl sydd â chyflyrau cronig](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [supporting people with chronic conditions](#).

CC06: Ymateb gan: | Response from: Emily Griffiths



Dear Senedd Health,

I am writing to you to express my views as of your evidence request regarding support for people with chronic conditions in Wales, I am more than happy for my submitted evidence to include my name when published but not my contact details.

I am writing to express my concerns about the non-existent support for those living with chronic conditions in Wales and I hope that my evidence will be taken into consideration and I will leave my contact details at the bottom of my email, if you wish to contact me. I am contacting you in regards to my own experience but I do work as a campaigner for the improvement of Women's Health and take the role seriously as I'm really disappointed how the Welsh Government is handling our care currently.

I am 24 years old, and currently I'm clinically diagnosed with Severe Endometriosis and Adenomyosis, Migraines, two rare conditions named Mast Cell Activation Syndrome and Diabetes Insipidus (as of which are both rare and I'm unable to receive sufficient care for these). Endometriosis and Adenomyosis are both common conditions but both take 9 years to diagnose and currently to treat the disease by highly skilled Excision surgery in Wales (which is unavailable) is at 9 years also. The accredited Endometriosis centre in Heath Cardiff and Swansea Bay are both in substantial crisis due to waiting times and demand for the services. There's a pure lack of Specialist Service Care and research in Wales for both common and rare conditions, including Women's Health Services, it's completely unacceptable. I have undergone nine long years of medical dismissal and medical gaslighting by medical professionals to receive my diagnosis of both Endometriosis and Adenomyosis, I almost lost my life to Sepsis due to this wait! I was told that I had Cancer in the most horrific way and then they changed my diagnosis to Endometriosis, my care in [REDACTED] has been a complete shambles and failure. Endometriosis and Adenomyosis is chronic and I have undergone two privately funded life saving surgeries in England, to remove the disease growths from my whole pelvic area, including nerves, my bowel was stuck to my bladder, I had a 25cm Endometrioma removed from my left ovary and cysts on my right ovary, I also had the disease on my ureters which almost led to me having kidney failure. Endometriosis is simply not a bad period and unfortunately Wales NHS were more than happy to leave me, thankfully I was able to privately fund my care in England - it's been medical neglect.

I'm now currently on Prostag injections which has now left me with bone damage due to the state of menopause I have been put in to and once again I'm not receiving care, I've been discharged from the Endometriosis Centres due to being 'out of area' and discharged from my local hospital because they can't treat me, as unwell as I am, I simply don't receive NHS Treatment in Wales. I'm continuously dismissed and judged by medical professionals, I feel because I'm a young woman and that's deeply unpleasant and unjust. All of this and no physical health treatment and neither support for mental health support for all continued medical trauma. The Welsh Government should be held accountable for this mess as I am not the only one treated like this, even though this is a chronic conditions consultation, I feel a consultation should be opened on Women's Health and Endometriosis in Wales, as the 'care' is unacceptable.

My contact details are: [REDACTED], I would be more than happy to discuss further.

Best regards, diolch
Emily Griffiths

[REDACTED]