

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](#).

CC04: Ymateb gan: | Response from: Rachael Gregory



Dear Sir / Madam,

I am currently a Midwife [REDACTED] and have the good fortune to have a Head of Midwifery [REDACTED] who is allowing me to work in a non clinical role due to my chronic health condition as many managers and employers would not be so considerate.

I have documented symptoms in my medical notes for my condition from the age of 14 ... I am now 54 and have only recently (April) been diagnosed as having Ehlers Danlos Syndrome which causes me amongst other things extreme fatigue, muscle joint and nerve pain , chronic migraines, frequent joint subluxation and dislocation, gastrointestinal problems including nausea, vomiting, severe reflux , decreased gut motility, bloating, abdominal pain; it is the cause of pelvic prolapses , abdominal hernias for which I have had surgery and dysautonomia which affects my heart rate and blood pressure causing fainting, confusion, brain fog etc.

I take a cocktail of unpleasant medication to ameliorate my symptoms... they do not get rid of them unfortunately but include Pregabalin for nerve pain which is a controlled drug , Topiramate which is an anticonvulsant and used to prevent migraine and reduces mine to a more manageable 10 or so a month, Proton pump inhibitor to reduce stomach acid so that my oesophagus doesn't become burnt or I aspirate acid when I reflux, strong pain killers etc I also often need to wear splints on my wrists and knees.

I have had to beg Doctors to listen to me for years and been made to feel like I'm wasting their time and now having finally been diagnosed by [REDACTED] a lovely Rheumatologist I find that due to lack of funding Rheumatologists in Wales DO NOT look after EDS patients despite this being the norm everywhere else and that there is no service for us.

EDS is complex and rare , we need to be at least under the umbrella of a specialist that a GP can refer to for advice but from what I can gather the closest specialist centre is the Mineral Hospital in Bath. Any other support is by patients themselves.

I was a General nurse for 25 years (trained in Llanelli General Hospital- Dyfed School of Nursing) before training as a Children's nurse in 2000 in Bristol and a Midwife in Swansea in 2013 and am sad that there are so many long term chronic conditions that have no services.

The effect of not having a proper service from a health provider has a huge knock on as I have found when trying to apply for PIP (this is a common theme having spoken to other EDS patients) as the ongoing symptoms which change daily can mean that some days we are unable to do any more than get up whereas on others we might be able to shower unaided. Many EDS patients use wheelchairs and don't qualify!

There has to be a better way forward.

Please get in touch if I can help this process in any further way as I have developed contacts that may be of assistance.

My contact details are below

Rachael Gregory

Rachael Gregory (RGN, RSCN, Bmid hons)

[REDACTED]
[REDACTED]