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Bwrdd Iechyd Prifysgol
Bae Abertawe
Swansea Bay University
Health Board

Cadeirydd/Chair: **Emma Woollett**
Prif Weithredwr/Chief Executive: **Mark Hackett**

gofalu am ein gilydd, cydweithio, gwella bob amser
caring for each other, working together, always improving

Rydym yn croesawu gohebiaeth yn y Gymraeg ac yn y Saesneg.
We welcome correspondence in Welsh or English.

Date: 24th June, 2022

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Jack Sargeant MS
Chair
Petitions Committee
Welsh Parliament
Cardiff Bay, Cardiff CF99 1SN
Petitions@senedd.wales

Dear Jack,

Re: Petition P-06-1240 Improve health services for people with epilepsy living in Wales

Thank you for your letter of 7th June 2022 requesting information about the services and resources that are in place to meet the needs of people with epilepsy living in our Health Board area, and asking if there are any gaps in services and resources at present. I'm happy to respond as follows:

In Swansea Bay in 2019, we faced a serious challenge to provide an epilepsy service (for patients with a common, long-term condition characterised by sudden and unpredictable fluctuations in seizure control), with limited resources. Issues included:

- long waiting times for first appointments;
- large numbers of patients on 'follow up not booked' (FUNB) waiting lists, and
- a lack of flexibility and responsiveness in the epilepsy service.

Prior to our service changes, waiting times to be seen in epilepsy clinics were 18 weeks for urgent cases and 23 weeks for routine cases. Waiting times to see the epilepsy specialist nurses (ESN) were 20 weeks. Moreover, there was a lack of flexibility to see patients, or to offer advice, at short notice, resulting in patients presenting to A&E and unnecessary hospital admissions. A 'first seizure' clinic was established in Swansea but waiting times for this could be as long as 16 weeks. A total of 1,394 patients were on epilepsy FUNB lists.



Pencadlys BIP Bae Abertawe, Un Porthfa Talbot, Port Talbot, SA12 7BR
Swansea Bay UHB Headquarters, One Talbot Gateway, Port Talbot, SA12 7BR
Bwrdd Iechyd Prifysgol Bae Abertawe yw enw gweithredu Bwrdd Iechyd Lleol Prifysgol Bae Abertawe
Swansea Bay University Health Board is the operational name of Swansea Bay University Local Health Board

We redesigned the SBUHB epilepsy service to try and overcome this challenge. In 2020, we introduced an 'Open Access' service model. This encourages patients to take ownership of their epilepsy care and reduces the number of appointments that they have to attend. Open access epilepsy clinics are designed for patients to be seen in a flexible and timely manner when their need is greatest. Instead of routine booked follow up appointments, patients are advised and encouraged to contact us via a telephone or email helpline with any issues. This helps prevent unnecessary hospital admissions and outpatient burden, and increases capacity for telephone advice and necessary follow up appointments, ensuring outpatient waiting times remain low.

Other service developments introduced during 2019-2020 included:

- providing rapid access to the first seizure clinic, for the prompt assessment and investigation of patients who have suffered a first epileptic seizure, which enabled patients to be discharged quickly from the emergency department;
- an email advice service to GPs, providing specialist epilepsy advice regarding their patient's epilepsy management (surveys have demonstrated a satisfaction rate of 98% amongst users);
- a weekly epilepsy multi-disciplinary team meeting to grade all epilepsy referrals, identifying those suitable for telephone or email advice;
- a triaging system run by an epilepsy co-ordinator who collects and screens all epilepsy referrals, monitors waiting times for appointments and maps capacity to demand, and
- development of a dissociative seizures service run jointly by a neuropsychologist and ESN.

Waiting times significantly improved:

Impact of Open Access Model		
Measure	Before	After
Total number of patients on FUNB lists	1,394	410
Total number breaching targets	784	116
Average waiting times for consultant epilepsy clinic (weeks)	21	3

Patients can now contact us immediately (via email or phone) to inform of us of changes in epilepsy control and will receive a response within 48 hours with clinical advice, including medication changes. From a patient perspective, the improvements mean:

- more virtual/telephone clinics;
- patients don't need to travel to clinic, particularly important as most are unable to drive;
- patients seen at times of need so more efficient consultations, and
- fewer non-attendances at appointments.

Regarding gaps in services and resources, the significant improvements described above have been made possible only by the appointment of a 2nd ESN and an epilepsy service coordinator. While service development is ongoing, waiting times and numbers are falling much more slowly as nurse caseload capacity has reached its limit. Even with the changes we have made, we are just about meeting demand for the most sick patients. We are failing

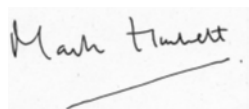


to offer specialist services such as antenatal and transition epilepsy clinics across the West Wales region.

The low numbers of ESNs in Wales (1 nurse per 2,195 patients) and in our region compare poorly to the Epilepsy Action recommendation (1:250), the Steers Report recommendation (1:300) and even the RCP recommendation (1:500). This is important because, having demonstrated in Swansea Bay how a small team can adapt to meet the challenge of providing a high quality and safe service for a common, long term condition, there is an opportunity to extend the open access model with Hywel Dda UHB (HDUHB).

We would offer one service to patients with epilepsy across the West Wales region, in keeping with the principles of our unique collaboration between Swansea Bay University Health Board, HDUHB and Swansea University, A Regional Collaboration for Health. We will look at the totality of demand and capacity in the region and work with HDUHB through our partnership arrangements in developing our future service plan.

Yours sincerely,



Mark Hackett
CEO

