



Ein cyf/Our ref: CEO.9114
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Dyddiad/Date: 11 July 2022

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Jack Sargeant AS/MS
Cadeirydd y Pwyllgor Deisebau/Chair of the Petitions Committee
Trwy ebost/By email: petitions@senedd.wales

Dear Chair

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

Thank you for your letter of 7 June 2022, in which you invited Hywel Dda University Health Board (the Health Board) to provide details of the current services available for Epilepsy patients and any gaps in resource that have been identified.

Epilepsy is the most common neurological condition, with approximately 30,000 cases of active disease in Wales. There are circa 4,000 in the Health Board, and circa 6,000 patients within the area of Swansea Bay University Health Board (SBUHB). Research shows that the prevalence of epilepsy is highest in areas of greatest deprivation, and is more common in people with a learning disability than in the general population - about 1 in 3 people (32%) who have a mild to moderate learning disability also have Epilepsy.

Epilepsy is associated with significant medical and social morbidity and is the second most common cause of neurological sudden death after stroke, for patients at much younger ages. As well as causing seizures, Epilepsy is associated with higher rates of mental health problems and significantly increased mortality. Individuals with Epilepsy have an overall 2-3 times higher risk of premature death than the general population, with a 20-fold increase in sudden death in young people with Epilepsy.

The Health Board recognises the needs of its Epileptic patients and is working in partnership with colleagues in SBUHB and A Regional Collaboration for Health (ARCH) to achieve the collective aim of providing a single unified regional Epilepsy service for the whole of SBUHB and the Health Board region. This service is based on the following key principles:

- prompt and accurate diagnosis for all patients with suspected Epilepsy
- increased self-management, improved psychological well-being and independence
- increased flexibility and availability of rapid access clinic slots
- prevention of unscheduled hospital admissions
- strengthened community based services and links with community health teams
- Improved services for patients with dissociative seizures

Currently, in the Health Board, Epilepsy patients are managed by the general Neurology service. A pre-existing capacity gap within that service has been exacerbated by the COVID-19 pandemic, with the service experiencing waiting time pressures.

The Health Board employs one full time Band 6 Adult Epilepsy Clinical Nurse Specialist (CNS) with a special interest in Learning Disabilities, one full time Band 6 Epilepsy CNS, and one part time (15 hours per week) Band 6 Epilepsy CNS, along with a Children's Nurse in Epilepsy.

More recently, to support patients and alleviate pressure on the service, the Health Board adopted an open access service facilitated through the three Band 6 CNS'. The service aims to encourage patients to take ownership of their Epilepsy care and reduce the number of appointments they have to attend. There are no longer routine booked follow-up appointments, but patients are advised and encouraged to contact the team via a telephone or email helpline for any issues. The establishment of open access Epilepsy clinics is designed to see patients in a flexible and timely manner, when their need is greatest. This helps prevent unnecessary hospital admissions by increasing capacity for telephone advice and follow-up appointments for patients, ensuring outpatient waiting times remain low.

As part of our ongoing improvement of the service, the Swansea Bay Regional Epilepsy Service (SBRES) identified the following:

- 1) A Band 7 Epilepsy Specialist Nurse (ESN) - this role would strengthen our Open Access Service which is seen as essential to epilepsy care in SBUHB. The ESN would also provide training provision for the most vulnerable patients and manage remote clinics. The ESN would attend the SBRES hub at Morriston Hospital one day per week for Multi-disciplinary Team (MDT) working, Continuous Personal Development and peer support.
- 2) The appointment of a full time Consultant Neurologist with an interest in Epilepsy – the post would provide a first seizure clinic, a specialist Epilepsy clinic and general Neurology clinics to Health Board patients. The consultant would also form part of the SBRES and attend MDT meetings in Morriston Hospital.
- 3) The current Epilepsy coordinator in SBUHB would become a Band 5 service coordinator, covering the regional epilepsy services. A Band 2 would then be appointed to assist the epilepsy nurses with basic administration support.

The team continues to liaise regularly with colleagues in SBUHB and work closely together to provide a regional response for our patients. Additionally, the Health Board attends the ARCH Neurological meetings, through which colleagues across the region work to continue improving service delivery and address the service needs that have been identified.

I trust this information is of assistance, but should you require any further details please do not hesitate to contact me once more.

Yours sincerely



Steve Moore
Chief Executive