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Bwrdd Iechyd Prifysgol
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Cardiff and Vale
University Health Board

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Suzanne Rankin
Chief Executive

23 June 2022

Jack Sargeant MS
Chair
Petitions Committee
Welsh Parliament
Cardiff Bay
Cardiff
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Dear Mr Sargeant

Petition P-06-1240 Improve Health Services for People with Epilepsy Living in Wales

Thank you for seeking our views on Petition P-06-1240 on the Improvement of Health Services for People with Epilepsy living in Wales.

You will recall that you posed the question "what services and resources are in place to meet the needs of people with epilepsy living in your Health Board area, and if there are any gaps in services and resources at present."

Following discussion with colleagues from our Specialist Services Clinical Board I provide the following response to your question – for convenience broken down into the sub-components of the overall question.

Services and resources in place to meet the needs of people living with epilepsy in Cardiff and the Vale

The Welsh Epilepsy Centre is based within Cardiff and Vale University Health Board ('the UHB'). It was established in the mid-1990s at University Hospital of Wales, and at that time provided services across South Wales. However, under current commissioning arrangements the UHB provides secondary care epilepsy for patients in our own and Cwm Taf Morgannwg UHB areas; this catchment population covers a population of approximately 700,000. Furthermore, current commissioning also requires the UHB to provide tertiary services (through a WHSSC funded programme), mainly for epilepsy surgery to a South Wales catchment population of 2.4M.

Outpatient activity in the epilepsy centre consists of on average 1300 new referrals each year, over 1400 under long term follow up review, along with an open access system to all patients reviewed previously. This allows patients to contact the department directly if they have concerns about their epilepsy without at times the need for outpatient appointment. Access through the telephone and email advice lines averages 5000 patient encounters per year, with most receiving instant access to care and changes in treatment where required. The suspected first seizures is an area of clinical priority for the department; NICE recommend that this patient type be reviewed within 14 days, and the current wait within the UHB is on average 22 days.

The centre delivers a multidisciplinary approach to epilepsy care and offers comprehensive services, across many platforms to include face to face and virtual. Current staffing of the centre is two Consultant Neurologists, and 4 WTE Adult Epilepsy Clinical Nurse Specialists. The Clinical Nurse Specialists are supported by the Consultant Neurologists and lead on follow-up outpatients, 1st seizure clinic, ante-natal clinics, outreach clinics at Cardiff prison, vagal nerve stimulator clinic and specialist prescribing for new treatments such as Epidiolex (cannabis oil) and Stirovento. The centre also has a unique Wales only service offering specialist assessment in the emergency unit by the epilepsy specialist nursing team, Monday to Friday, 08.30–1630 hours. The epilepsy surgery programme, pre-surgical evaluation to surgery and follow up is based in Cardiff alongside the Neurosurgery Department.

Patients with epilepsy are also seen and managed by local neurologists and learning disability specialists and teams.

The centre's close links with other departments within the UHB (paediatric neurology, psychiatry, learning disabilities, antenatal, clinical pharmacology, ophthalmology, clinical psychology, neuroradiology, neurophysiology and neurosurgery) enables patients to receive treatments most appropriate to their circumstances. It is also research active, undertaking and recruiting to various local, national and international trials to ensure patients have access to cutting edge care.

The Epilepsy teams across three health boards (Cardiff and Vale, Swansea Bay and Aneurin Bevan) continue to work through a clinical network with quarterly meetings. This collective approach has resulted in publication of a First Seizure Pathway (2021). The group continue to work on refinement of an epilepsy data dashboard which will be critical to informing future understanding of epilepsy epidemiology and need.

Current Gaps in Services and Resources

Whilst the service is comprehensive and safe there are nonetheless gaps in provision.

At the onset of the COVID-19 pandemic the dedicated epilepsy outpatient facilities was stepped down, and relocated to meet national social distancing guidelines.

Presently the epilepsy centre has limited footfall available at the University Hospital of Wales, with the all outpatient activity taking place at another site (Rookwood Hospital). The essential inpatient telemetry service was suspended during the pandemic, it has now reopened but is not yet operating at pre-COVID levels. This is due to the telemetry service currently utilising a footprint within a non-neurology inpatient area. This has impacted on the epilepsy surgery programme which remains fragile. We have insufficient outpatient capacity to ensure timely new and follow up appointments.

It is notable that there is an increasing patient demand within these new and follow up appointments. This increase occurs because of an increase in the provision of medicines requiring specialist prescription or monitoring, and a change in practice to repatriate to the epilepsy centre prescriptions in all women of child bearing age taking sodium valproate.

Patients within the Cwm Taf Morgannwg UHB population access clinical nurse specialist support from the service within Cardiff. Whilst this service is comprehensive and safe there would be some merit in Cwm Taf Morgannwg UHB commissioning the service locally to enable patient access in their own locality. Cardiff and Vale UHB have recommended this option to Cwm Taf Morgannwg, and if requested we are able to provide the commissioning process with supporting data and evidence.

There is currently no psychology provision for patients within Cardiff and Vale and Cwm Taf Morgannwg Health Boards, despite there being a recommendation in NICE guidelines for the management of epilepsy in children, young people and adults. Access to psychology services would be of real benefit to the epilepsy population, particularly at the point of diagnosis. The service does mitigate the risk via regular clinical review and access to the CNS team. However, additional investment would be required to establish a service that provides comprehensive health psychology support to this patient group and work has commenced on the development of a business case for psychology support.

The service is currently experiencing increased patient demand to see a consultant neurologist which has increased the overall weeks wait for patients to be seen in a clinic setting. There are plans in place to resolve some of these issues. The clinical team have put in place several systems to address this such as:

- Open Access: Where patients with urgent clinical questions / needs can contact the clinical team and receive clinical input within 24hrs.
- Epilepsy Telephone Helpline: This service allows allow to the CNS and Medical Team to provide clinical information to other healthcare professional and patient (Monday-Friday 9am-5pm).
- Weekly Multi-Disciplinary Team Meetings at which all referrals into the department are reviewed and appointed on clinical need.

With the increase demands on the service the waiting time for patients triaged as 'routine' have increased, although for those triaged as urgent the waiting times are similar compared to periods before the pandemic and before the altered clinical pathway requiring specialist prescribing or pharmaceutical monitoring. The consultant neurologist clinical team are reassured that all patients have access to expert clinical advice via the nursing and medical teams when needed via the services listed above.

Discussions regarding the epilepsy centre footprint and outpatient recovery plans are ongoing as the UHB restore services following the pandemic response. Outpatient services will continue to be delivered from Rookwood Hospital until outpatient facilities are provided on the University Hospital Wales site. We recognise that even when the epilepsy outpatient services return to their original footprint on this site there will still be a requirement for an optimised location to encompass the whole of the epilepsy service and gain maximal benefit from the telemetry capability. The UHB are in the initial stages of developing a case for capital funding to establish a future outpatient and day case facility at University Hospital Wales.

Clear challenges have arisen from the pandemic and the essential improvements in the epilepsy care pathway necessitating increased specialist activity. Nonetheless, the Welsh Epilepsy Centre, in partnership with other Health Boards, has adapted to fit the needs of the ever changing post pandemic health service and it continues to provide the best care that it can to patients with epilepsy, their families and carers. Furthermore, the Welsh Epilepsy Centre recognises its future development needs and can, subject to capital investment, design an optimised and future proofed service.

Yours sincerely



Suzanne Rankin
Chief Executive