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Mental Health & Learning Disabilities Directorate

Epilepsy Services Update February 2023

Situation

- Prior to June 2021, Learning Disability Services provided a specialist clinic for people with learning disabilities diagnosed with epilepsy. The clinic was based in Carmarthen and consisted of a psychiatrist with a specialist knowledge of epilepsy who was embedded within the Neurology Service and a learning disability nurse with a special interest in epilepsy. The service was delivered via an outpatient clinic and provided community visits as appropriate. In June 2021, both the psychiatrist and the nurse left the organisation. As a result of this, the clinic was no longer able to be provided.
- Subsequently, a caseload/desktop review was undertaken of all patients, of which there were 170, known to the clinic. This review was undertaken by the Community Learning Disability Team (CTLD) Managers (by geographical location). A key outcome of the review revealed paper based record keeping processes and outstanding patient reviews.

Action Taken

- In June 2022 a further review of the patient caseload was undertaken to establish their position in terms of awaiting a Neurology appointment and action taken to either:
 - Discharge from CTLD to Primary Care for GP medical oversight only (with an open referral back to CTLD and Neurology if required)
 - Remain on CTLD caseload with nursing input by CTLD nurses, and medical oversight provided by either Consultant Psychiatrist or GP
 - Remain on CTLD caseload with nursing input by CTLD nurses, and referred to Neurology for medical oversight.
- All Epilepsy Management Plans were reviewed within the CTLD team, prioritising those individuals who had not been seen within the previous 12 months. Audit forms for Epilepsy management have been updated, to identify whether there is a management plan, risk assessment, rescue medication plan and Valproate – Annual Risk Acknowledgement Form (ARAF) in place. The CTLDs provide a service to GPs to review epilepsy management plans, for those under primary care.
- A rolling programme of future audits has been initiated and will be monitored through a monthly compliance meeting within service.

Action Taken

- The ARCH Neurosciences Programme Meeting action plan includes the development of Regional Services for Epilepsy as an action – meetings have taken place between Swansea Bay LD leads and Hywel Dda leads to understand how the pathway works and any opportunities for developing services explored.
- Advertisements for two Psychiatry vacancies have been made and there has been some interest expressed from an experienced Psychiatrist working elsewhere, wishing to re-locate to Pembrokeshire.
- There has been a re-structuring to align the Head of Service to take a lead on operational management of the LD Community and Inpatient Services.
- An additional Epilepsy Nurse has been appointed to join the Epilepsy Nursing Team.
- Any follow up actions from Neurology Clinical appointments are forwarded to the Epilepsy Nursing Team and the Learning Disability Nurse in the Team ensures these are completed, linking where appropriate with the Community Learning Disability Team. There is a workplan in place, agreed by managers from both the Learning Disability service and Chronic Condition Management

Action Taken

- An external review has been commissioned, led by Professor Rohit Shankar, Consultant in developmental Neuropsychiatry and Clinical Director at Cornwall Partnership NHS.
- Questionnaires were issued and returned from staff, patients and carers however the return rate was a little disappointing with only 54 responses. Following further engagement and meetings with family members and carers, an electronic email version was requested which has been developed and the deadline for return of the questionnaires has been extended to 1 March 2023.
- The comprehensive review will define the functions and roles for the management of epilepsy in line with NICE guidelines (Epilepsy in Adults, 2013), undertaken by the internationally accredited author of the current UK national guidance on LD epilepsy pathways. The service is linking with families and carers, to ensure individuals remain supported whilst the review is completed and has developed close working relationship with the Health Board's Neurology service, ensuring urgent appointments and access to specialist advice are prioritised. Once the review has been concluded, a report outlining the findings and next steps will be brought to Quality, Safety and Experience Committee (QSEC).

Recommendation

- For QSEC to take assurance by the actions taken to review the Epilepsy pathway in the Learning Disabilities Service.