

STANDARD OPERATING PROCEDURE

Learning Disability Epilepsy Service

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Author/Lead Job Title	Jenny Crofts Epilepsy Specialist Nurse
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VALIDITY – All local SOPS should be accessed via the Trust intranet

CHANGE RECORD

Version	Date	Change details
1.0	July 2024	New SOP. Approved at Children & LD Clinical Governance (4 July 2024).

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1. INTRODUCTION

The Learning Disability Epilepsy Service provides supports to adults with Learning Disabilities and complex epilepsy across Hull and East Riding. It is widely acknowledged that there are potentially many barriers to care for this complex group of individuals. Epilepsy is one of the most common neurological conditions affecting around 1 in 100 people. For people with learning disability this increases to around 1 in 5 people emphasising the importance of ensuring comprehensive, robust services to ensure the needs of this demographic are met.

This standard operating procedure is informed by NICE Guideline Epilepsies: Diagnosis and management ([Overview | Epilepsies in children, young people and adults | Guidance | NICE](#)). The guidance is very clear that all services need to ensure they provided adjustments are for people with learning disabilities to have access to equitable services. The Learning Disability Mortality (death) Review (LeDeR) has consistently noted Epilepsy as one on the four main reasons for death in people with learning disability ([Learning Disabilities Mortality Review Programme | School for Policy Studies | University of Bristol](#)). It was agreed in Hull and East riding this would be achieved by providing a specialist learning disability service that would still be led by a Consultant Neurologist.

2. SCOPE

This Standard Operating Procedure (SOP) covers the Adult Learning Disability Epilepsy service for Hull and East Riding. The service is a Neurology led service. We have a Consultant Neurologist whose time is procured from Hull University Teaching Hospital for two sessions per month. There are full time Specialist Epilepsy Nurses in the team including at least one non-Medical prescriber and Administration Support employed directly by Humber Teaching NHS Foundation Trust. The service provides clinical consultation via face to face, telephone and virtual clinics, home visits. Specialist Epilepsy Initial assessment are carried out by the Epilepsy Specialist nurses that include consideration of differential diagnosis, complex co-morbidities and the wider biopsychosocial factors in the individual's life. The Service works in a fully multi-disciplinary manner sitting in the Community Learning Disability Team (CTLD). There is also wider MDT working to include services such as the Learning disability Intensive support team, Social Services, Hospital Liaison, care providers, Continuing Health Care, Acute services, Childrens services in relation to transition and others as required.

The SOP should be read in consultation with the following documents:

- Mental Capacity Act and Best Interests Decision Making Policy
- Mental Health Act Policy
- NICE Guidelines. Epilepsies: Diagnosis and management (CG137)
- NICE Quality Standards (QS211) Epilepsies in Children, young people and adults.
- NICE Transient loss of Consciousness (Blackouts) in over 16's (CG109)
- National LD professional Senate Guidance 2023
- Intensive support Team SOP
- Lone Working Policy
- Was Not Brought Policy

3. DUTIES AND RESPONSIBILITIES

Consultant Neurologist

Provide a Neurology lead for the service holding a caseload of all the patients referred to the service as advised under NICE. The Consultant also holds clinics both face to face and via teams. They provide clinical supervision for the specialist nurses twice monthly at the clinics but are available in between via email or telephone if required for addition support. This can be to discuss complex

cases, new medications and prescribing that it outside the scope of the Nurse prescribers' scope of practice. They will ensure that information is disseminated in relation to wider trends and national focus in epilepsy. This ensure that the Learning disability aspect of the service is not isolated from the wider Neurology service. Act as liaison and link between Acute and community services as appropriate. The link between all aspects of Neurology is essential to ensure that equitable care is available for people with a learning disability and epilepsy as outlined in the NICE Guidelines.

Epilepsy Specialist Nurse – Lead

The Lead Nurse holds a clinical caseload. This is agreed with the specialist Nurse. The caseloads are balanced between clinicians in relation to complexity and demand. Due to the nature of the condition an individual's needs and vary quite significantly. It is understood there may need to be flexibility and a dynamic approach to manage the patient's needs. The Epilepsy Specialist Nurse Lead has the role of leading the Learning Disability Epilepsy service and ensure that practice remains current in consultation with the Consultant Neurologist. Ensuring information and policy along with any associated documentation is disseminated multi-directionally throughout the team and wider CTLD when appropriate. They can provide supervision and training to other Nurse(s) in the team. Ensure that other Nurse(s) have the appropriate opportunity to access regional and national training opportunities. To perform the role of a Clinical Lead within the wider Community Team Learning Disabilities. Plan, develop, over see any business planning, and deliver epilepsy awareness and Buccal Midazolam training within the Trust and to other service providers. The Nurse will work to the learning Disability epilepsy specialist nurse competency framework ([The-Competency-Framework-for-Registered-Nurses-Providing-Specialist-Epilepsy-Care.pdf \(esna-online.org\)](#)).

Epilepsy Specialist Nurse(s)

The Epilepsy Specialist Nurse holds a clinical caseload. This is agreed with the Lead Nurse. The caseloads are balanced between clinicians in relation to complexity and demand. Due to the nature of the condition an individual's needs and vary quite significantly. It is understood there may need to be flexibility and a dynamic approach to manage the patient's needs. The epilepsy Specialist Nurse will follow the lead and direction of the Consultant Neurologist and Lead Specialist Nurse. They will be responsible to ensure that they are aware of information and policies to be followed including the completion of appropriate documentation. They should alert the Lead Nurse to any training requirements they may have. To attend training opportunities and conferences when offered. To work alongside and support the Lead Nurse in the future development of the Learning Disability Epilepsy service. Plan, develop and deliver epilepsy awareness and Buccal Midazolam training within the Trust and to other service providers. The Nurse will work to the learning Disability epilepsy specialist nurse competency framework ([The-Competency-Framework-for-Registered-Nurses-Providing-Specialist-Epilepsy-Care.pdf \(esna-online.org\)](#)).

Administration Support

To complete administrative tasks for the Learning Disability Epilepsy service as required. To complete audio typing of clinical letters, type assessments and reports. Support in the planning of clinics, generation of clinic letters and associated documentation. Help organize, manage, and develop resources for the training that is delivered by Nurses. Support in the development and maintenance of databases etc. to help performance and quality management. This list is not exhaustive and other tasks may be required as appropriate to the grade and delegated by the specialist nurse.

4. PROCEDURES

Referrals will follow the existing CTLD referral Pathways and processed following current protocols and documentation.

The criteria for the service is that individuals must be aged 18 years, have a learning disability and epilepsy. The CTLD referral pathways will ensure that the first two aspects of the criteria are met. The service does not hold a waiting list as this is deemed clinically unsafe.

All new referrals that have not been seen by the team before will have an Initial epilepsy assessment started within two weeks of referral as per NICE Guideline CG137. This will help establish if the individual has a clear diagnosis of epilepsy. If a person has epilepsy and their care is being delivered from another Neurology Service then consideration would have to be given to if it is appropriate and, in their best interest for this to continue. If a person is under the care of more than one clinical specialist, it can lead to confusion and a lack of clarity so it may be that a decision is required as to who is going to be the care provider.

Once the assessment is completed all new referrals will be initially assessed by the Consultant Neurologist within 12 weeks.

Re-referrals will have their previous epilepsy assessment reviewed and updated as appropriate. Following assessment, it will be decided on clinical need if the next appointment will be with the Prescribing Specialist Nurse or the Consultant Neurologist. Once individuals are accepted on the caseload and have been assessed they will have an individualised epilepsy Management Plan formulated (NICE CG137).

The service will carry out reviews using a blended model of care including, face to face clinics, home visits, telephone consultation and virtual consultation. These can be carried out by either a Nurse or the Consultant Neurologist (except home visits which will be purely Nurse) to ensure reasonable adjustments are made for individualised patient centred care. Review intervals will be clinically determined depending on the clinical presentation of the individual, if there are any changes to treatment or changes in the individual's health. The patient, their families and/or carers will be encouraged to contact their service if there are any changes in presentation in between reviews. In line with NICE Guidelines (CG137) all Women of childbearing age and men who are prescribed a Valproate based medication will follow the Valproate safety Guidelines (2024) appropriately. This is detailed instruction which must be followed, or steps which must be taken to implement the document.

4.1. Consultation

New referrals

All new referrals will have an Initial Epilepsy Assessment completed by one of the Nurse specialists (appendix A). They will then be seen by the Consultant Neurologist in a clinic. At initial assessment it will be assessed as part of reasonable adjustments if this will be face to face or video depending on the individual's needs. For example, some with Downs Syndrome and Dementia may become very distressed traveling to clinic and the Nurse Specialist can see them at home to collect information and then a video consultation with the Consultant and Nurse present in the meeting would be less distressing. Other situations such as if the patient has a movement disorder that needs a physical examination, then a face-to-face consultation will be booked.

Face to face clinic

All face-to-face consultations will meet with infection prevention and control guidance. Any policies and procedures in relation to this will be followed as appropriate and may influence the decision making as to what appointment is offered as part of the risk assessment and management process. At present these will be held at Highlands Health Centre. Individuals will be seen on a clinical need's basis. This includes Vagal Nerve Stimulation (VNS) patients, new patients and clinically complex patients. If another venue becomes available, then consideration will be given to if this may be added to the service model.

Video Clinics

These will be held via MS Teams and arranged by the Learning Disability Epilepsy Admin. This will ensure Information Governance / Data protection is met. Alternative platforms would be considered if they became available. This format will allow the Consultant Neurologist to consult with patients/carers without the need for them to attend face to face clinics but still be able to see the patient to carry out assessment. This will ensure quality care and relationship building whilst reducing stress, anxiety and infection risk. These may be offered to new patients, re-referrals or on-going

reviews as clinically indicated. Consultant Video clinics to be held Monthly. Specialist Nurse video clinics can be held as required and will allow for care home reviews with put the need to attend the home and therefor reduce the risk of infection. They are also a valuable tool when working with a wide complex multi-disciplinary team.

Telephone clinics

Primarily these will be Specialist Nurse Clinics held on a monthly basis at least. This will allow the Specialist Nurses to carry out routine reviews with patients/carers. They will be decided on clinical need as will the review interval. The Consultant Neurologist may carry out some telephone reviews under certain circumstances for example to review particular medications that may be under special status and can only be prescribed from the Hospital (E.g., at time of writing Epidiolex).

Home visits

The Specialist Nurses will carry these out to complete initial and ongoing clinical assessments. Home visits may be carried out to review VNS if the individual cannot attend clinic, or the generator needs reviewing in between face-to-face clinic sessions. When home visits take place the Trust Lone working policy will be followed.

4.2. Patient Initiated Follow Up (PIFU) and discharge.

Due to the complex needs and co-morbidities of the people we support PIFU is complex to initiate as a model on its own. All follow up has to be patient centered to meet the specific needs of the individual, their care needs and setting. The majority of people who access the service do not have the capacity to consent under the Mental Capacity Act due to their Learning Disability and cannot initiate follow up appointments independently. Family/Carers are relied on to do this on their behalf in their best interests. The trust Did not Bring Policy will be followed if required. Before an individual is discharged and when the review schedule is being considered a complex clinical assessment is undertaken by the clinician. Clinicians will assess the complexity of the individual's co-morbidities and how they impact on their epilepsy. Alongside this they will also assess the complexity of the individuals care environment, (are they cared for just by family? Do they have respite care? Do they live in a care home type environment? etc.) and how that may impact on the consistency of follow up care and information. If it assessed that someone's epilepsy is stable, their co-morbidities are stable, their care environment is stable, and carers are able to inform if there are any changes then the interval of review may be increased. After all review family/carers are informed that they can contact the team if they have any concerns and a review can take place sooner than planned if required. This is in line with 2021/2022 Priorities and Operational planning guidance [Briefing template \(england.nhs.uk\)](#)

People will be discharged from the service back to GP care if their Epilepsy becomes stable and all parties involved are in agreement that it is in the patient's best interests. This does not always mean they will be seizure free at this point. The discharge pathway is through the CTLD team meetings with letters to the GP and patient/carer.

4.3. Specialist pathways

Vagal nerve stimulator (VNS)

Individuals can be considered for VNS if they have drug resistant epilepsy meaning that they have tried two or more anti-seizure medications and continue to have seizures. This is the same for people with a learning disability. Consideration may be given to other co-occurring health conditions that could affect their risks in relation to surgery. The individual's capacity needs to be assessed and then if required a decision made in the person's best interest. If it is agreed with the individual, their carer, the specialist Nurse and Neurologist then a referral is made to the Neurosurgical team at the hospital. The Consultant Neurosurgeon will then consider the individual referral and meet the patient and family. The Consultant Neurosurgeon is the decision maker as to if this is to proceed under best interest. The process in relation to VNS insertion is managed by the hospital. The Epilepsy specialist nurses will be informed once a date is set for insertion and receive a letter following surgery to ensure that all details are shared. The specialist nurses have access the Hospital Lorenzo to review clinical records for additional safety. (See appendix B.)

Epilepsy specialist nurses will follow the patient up and review the patient to ensure that the VNS settings are adjusted and optimized. Over time the VNS battery will require replacement. At that point further discussion will be had and if it is agreed in Best interests then a referral will be made back to neurosurgery for the generator to be replaced.

Down Syndrome dementia

It is understood that between 10-20% of people with dementia develop epilepsy. Any referral for an individual with Down syndrome, dementia or suspected dementia and new onset seizures will be assessed. Consideration will be given to differential diagnosis. They will be reviewed by the Consultant Neurologist as all new Patients. During this consultation consideration will be given as to any further investigations and their appropriateness. This will be considered individually and if required in best interests. If a diagnosis of Epilepsy is given and medication commenced, it is anticipated that in most cases the individual will remain on the Epilepsy case load until end of life. This will ensure that advanced care planning can take place and prevent hospital admission due to seizure. Individualized approaches and care plans to support medication administration can be developed as required. Medication formulation can also be adapted to consider dysphagia etc. working alongside Speech and Language therapy.

Sudden Unexpected Death in Epilepsy (SUDEP)

This is when no other cause from death can be found in someone with epilepsy. 1 in 1000 people with epilepsy die from SUDEP each year. No one knows the cause, but most deaths occur at night or during sleep. The person may have had a seizure, but this is not known. At this time SUDEP can't be prevent but reducing risks can help. The epilepsy specialist nurses will work with the patient, families' carers and the MDT to ensure therapies are supported as well as possible, seizures are monitored appropriately, all patients have individualized management plans, care providers have suitable risk assessments in place.

Medication optimization and STOMP

Although Anti-seizure medication is not prescribed under the remit of STOMP some of the medication hold dual classification and therefore may be considered as such. Some individuals may be prescribed medication for a dual function to help stabilize mood and for seizures. When adjusting medication consideration needs to be given to seizure control and the potential for impact on mood and vice versa. This may be the responsibility of the Specialist Nurse prescriber or Consultant Neurologist.

4.4. Multi-disciplinary team working

The service sits within the community learning disability team but works in very close conjunction with a wide multi-disciplinary team (MDT). All clinical information such as letters and management plans are shared with not only primary care but also the Acute Trust. This ensure if a patient is admitted with any health condition their care is continuous and safe. The service works closely with the Learning disability liaison nurse to ensure that they are informed of acute admissions. At this point the Neurology medical team, including Consultants and Junior Doctors, will be emailed and information shared. Epilepsy specialist Nurses have access to the Hospital Lorenzo system to ensure that clinical information can be obtained in a timely manner. This then can inform clinical decision making and ensure that treatment is not delayed.

Transition

There is a transition pathway from children's epilepsy services that is constantly being considered. It is known that this is a difficult time an individual's life. Meetings are held between adult and pediatric services throughout the year to review which patients are approaching transition. Following each meeting an individualized approach is taken appointments and hand over of care for each patient. This may be through joint clinics, home or school visits etc. There is not set path is it will depend on the individual need. The usual external referral process will need to be followed once the individual reaches the age of 18 years.

4.5. Training

Epilepsy specialist Nurse will deliver training to ensure carers are aware how to safely administer Buccal Midazolam. This training has been developed in line with the Epilepsy Specialist Nurse Association guidelines ([Best practice guidelines for training professional carers in the administration of Buccal \(Oromucosal\) Midazolam : ESNA - Epilepsy Nurses Association \(esna-online.org\)](#)). This will be delivered virtually on a monthly basis. It will also be available as part of the wider Epilepsy awareness training that will be delivered face to face. Epilepsy awareness training will also be available to be delivered by both Epilepsy Specialist Nurses. This will be available for Trust staff and for external providers to purchase. It will be delivered face to face on a monthly basis for people to book on to. The training will broadly cover what causes epilepsy and the different types of seizure, challenges in diagnosis and treatment, risks related to epilepsy, it's treatment and the impact on quality of life and how to support and person having a seizure. Bespoke training will also be available as required in relation to specialized areas of care such as VNS and non-epileptic seizures.

5. REFERENCES

The competency framework for registered nurses providing specialist care for those with a diagnosis of epilepsy and learning disability (2023) [The-Competency-Framework-for-Registered-Nurses-Providing-Specialist-Epilepsy-Care.pdf \(esna-online.org\)](#).

2021/22 priorities and operational planning guidance. [Briefing template \(england.nhs.uk\)](#)

Best practice guidelines for training professional carers in the administration of Buccal (Oromucosal) Midazolam for the treatment of prolonged and/or cluster epileptic seizures in the community. [Midazolam-interim-guidelines-MI_12454014_21.12.23_V_3.pdf \(esna-online.org\)](#)

The Mental Capacity Act (2005). [Mental Capacity Act \(2005\) \(humber.nhs.uk\)](#)

NICE [Epilepsies: Diagnosis and treatment CG137. Epilepsies: diagnosis and management | Guidance | NICE](#)

NICE Transient loss of consciousness ('blackouts') in over 16s CG109. [Overview | Transient loss of consciousness \('blackouts'\) in over 16s | Guidance | NICE](#)

Delivering effective Specialist community learning [disability](#) health teams/ services for adults [with](#) learning disabilities and their families and carers(2023). [Delivering Effective Specialist Community Learning Disabilities Health Team Support \(bild.org.uk\)](#)

Humber Teaching NHS Foundation Trust Lone working policy [Lone Worker Policy F-004.pdf \(humber.nhs.uk\)](#)

Humber Teaching NHS Foundation Trust [Was not brought policy Was Not Brought and No Engagement Policy N-072.pdf \(humber.nhs.uk\)](#)

Appendix A: VNS Pathways

Referral for Vagal Nerve Stimulation (VNS).

Any referral for VNS needs to meet the criteria as set out by NHS England ([Vagal-nerve-stimulation-for-epilepsy.pdf \(england.nhs.uk\)](https://www.england.nhs.uk/vagal-nerve-stimulation-for-epilepsy.pdf)). VNS is commissioned for adults and children who meet all the criteria in either section A or B as indicated below, as appropriate to their clinical circumstances.

A. Medically Refractory Focal-Onset Seizures

The patient has medically refractory focal-onset seizures. Medically refractory means seizures that occur in spite of therapeutic levels of anti-epileptic drugs or seizures that cannot be treated with therapeutic levels of anti-epileptic drugs because of intolerable adverse side effects.

AND

The patient has failed or is not eligible for respective surgery.

AND

At least 2 complex partial seizures per month OR recurrent life-threatening status epilepticus
3 first line anti-epileptic drugs have been tried over a period of at least 2 year.

OR

B. Medically Refractory Generalised Seizures

The patient has medically refractory generalised seizures. Medically refractory means seizures that occur in spite of therapeutic levels of anti-epileptic drugs or seizures that cannot be treated with therapeutic levels of anti-epileptic drugs because of intolerable adverse side effects.

AND

The patient has failed or is not suitable for respective surgery.

AND

At least 1 generalised seizure per month OR recurrent life-threatening status epilepticus
3 first line anti-epileptic drugs have been tried over a period of at least 2 years

VNS is not commissioned as set out below:

C. Exclusion criteria

The following criteria will exclude a patient from approval for VNS.

- For treatment of patients with seizures other than focal-onset seizures or medically refractory generalised seizures
- For patients who can be treated successfully with anti-epileptic drugs and / or ketogenic diet
- For treatment of patients with depression in isolation
- For the treatment of essential tremor in isolation
- For the treatment of headaches in isolation
- For the treatment of obesity in isolation

Consideration for insertion of VNS for people with a learning disability may need to be considered in the individuals' best interest if it is agreed that they lack capacity in relation to the decision.

All discussions in relation to VNS need to include the following people:

The patient and their carers

Consultant Neurologist

Epilepsy specialist nurse

Consultant Neurosurgeon

Process for initial insertion of VNS

After identifying an individual who meets the criteria appropriate clinical discussions can be held. If it is agreed that it the individual should be put forward for consideration by the

Neurosurgeons, then the specialist nurses will write asking for their consideration. If this is being done in best interest, then the appropriate documentation will be shared at that point. The individual will be given an appointment to be reviewed by Neurosurgery before being offered any further appointments.

The decision relating to surgery and possible surgical risks, if being taken in best interest, will sit with the Surgeon.

The surgical team will be responsible for informing the specialist nurses of the date for the surgery. The specialist nurses will work with the patient, carers and hospital team to consider if any reasonable adjustments may be required to support individuals. Patients will be given post-surgical advice on discharge in relation to wound care.

Surgery is performed under the care of the neurosurgeons. The VNS generators are switched on and checked to be functioning on by the neurosurgeon/the LivaNova team whilst in theatre. The information relating to the individuals' settings is shared with the epilepsy Specialist Nurses by LivaNova post-surgery.

Four weeks post-surgery individuals will be followed up by the specialist nurses to ensure that ramp up and setting adjustments can take place. From this point on adjusting of the device settings will remain with the Specialist Nurses.

Replacement of VNS

Consideration for replacement of VNS for people with a learning disability may need to be considered in the individuals' best interest if it is agreed that they lack capacity in relation to the decision.

Once it has been agreed that it is appropriate to replace a generator due to the battery being low then the specialist nurses will write to Neurosurgery making this request. If it is appropriate best interest documentation will be included.

The individual will be given an appointment to be reviewed by Neurosurgery before being offered any further appointments.

The decision relating to surgery and possible surgical risks, if being taken in best interest, will sit with the Surgeon.

The surgical team will be responsible for informing the specialist nurses of the date for the surgery. The specialist nurses will work with the patient, carers and hospital team to consider if any reasonable adjustments may be required to support individuals. Patients will be given post-surgical advice on discharge in relation to wound care.

Surgery is performed under the care of the neurosurgeons. The VNS generators are switched on and checked to be functioning on by the neurosurgeon/the LivaNova team whilst in theatre. The information relating to the individuals' settings is shared with the epilepsy Specialist Nurses by LivaNova post-surgery.

Four weeks post-surgery individuals will be followed up by the specialist nurses to ensure that ramp up and setting adjustments can take place. From this point on adjusting of the device settings will remain with the Specialist Nurses.

Management of VNS

Within the community this will remain with the Epilepsy specialist Nurses. Patients and carers will know how to contact the Specialist Nurses. Routine reviews will be offered at appropriate intervals. These will vary depending on individual clinical need.

If the Specialist nurse has any significant clinical concerns relating to the generator when reviewing, they can contact LivaNova clinical representatives directly for advice and support. If

on review the Epilepsy Specialist Nurse feels that it is indicated that there is a lead break, they can contact the patients Neurologist or the on-call Neurologist who can arrange for a penetrated chest x-ray. This may indicate that a further referral is need for surgery to replace the lead.

If a patient has an acute admission to hospital, then management of the VNS is under that of the Hospital trust.

If a patient has a lost or significantly damaged magnet, then they or the carers should contact the Epilepsy specialist Nurse who can arrange for replacement to be supplied. The Epilepsy Specialist nurse obtain the magnets from LivaNova directly. There is no charge for magnets, but individuals should be aware that they are responsible for ensure the good care of them.

Other references

[8 Non-pharmacological treatments | Epilepsies in children, young people and adults | Guidance | NICE](#)

Appendix B: Epilepsy Learning Disability Assessment

EPILEPSY LEARNING DISABILITY ASSESSMENT

SECTION 1 - CLIENT DETAILS N.H.S.NUMBER:

NAME: _____ **DATE OF BIRTH:** _____

ADDRESS: _____ **UNIT NUMBER:** _____

Care name: _____ **TELEPHONE NO:** _____

Address: _____ **EMAIL ADDRESS:** _____

Relationship: _____

Contact details: _____

TEL: _____

EMAIL: _____

GENERAL PRACTITIONER:

TELEPHONE No: _____

OTHER PROFESSIONALS INVOLVED:

NAME	ROLE	CONTACT

Dose the individual have capacity to consent to this assessment? Yes No
Is the assessment being carried out in their best interest? Yes No

Mental Capacity – Does the person have Capacity to video of possible seizures been taken and shared if required? Yes No

If No, is it agreed in the person’s Best Interests to film and share to help inform Differential Diagnosis?

Clinic preference:

Telephone: Yes No

Video: Yes No

Face to face: Yes No

SECTION 2 EPILEPSY MEDICAL HISTORY/INVESTIGATIONS

Include details of first seizure, cause of epilepsy, medical problems, previous and current seizure pattern

Are there any Known seizure triggers?

SECTION 3 – Seizure Description

1. TYPE OF SEIZURE: _____

<p>Description</p> <p>Usual duration of seizure:</p>
--

2. TYPE OF SEIZURE: _____

<p>Description</p> <p>Usual duration of seizure:</p>
--

3. TYPE OF SEIZURE: _____

<p>Description</p> <p>Usual duration of seizure:</p>
--

4. TYPE OF SEIZURE: _____

<p>Description</p> <p>Usual duration of seizure:</p>
--

Vagal nerve Stimulator

<p>Yes – give details</p>	<p>No – give reason</p>
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WHAT HAPPENS IN AN EMERGENCY SITUATION for example Status epilepticus, clusters of seizures?

Is there a written Management plan for the emergency situation? Please give details.

HOW AND WHERE ARE THE SEIZURES RECORDED?

DOES THE CLIENT HAVE NON EPILEPTIC EVENTS? Please indicate below giving descriptions of the episodes:

Previous investigations:

TYPE OF INVESTIGATION	DATES	RESULTS, IF KNOWN
CT (Computed Tomography)		
EEG (Electroencephalogram)		
MRI (Magnetic Resonance Imaging)		
BLOOD TESTS		
MEDICATION REVIEW		
EKG		

SECTION 5 - INFORMATION ABOUT EPILEPSY

Has parent/client been given information regarding epilepsy? (Sign post to information if required)

SECTION 6 – IMPACT OF EPILEPSY ON QUALITY OF LIFE / RISK

1. SOCIAL/LIFE

2. TRANSPORT

3. DAY CARE/EMPLOYMENT/EDUCATION

4. MEDICATION-Including administration of emergency treatment

5. RESPITE CARE

6. CONTRACEPTION

7. SLEEP PATTERN

8. ASSISITVE/ SUPPORTIVE TECHNOLOGY

9. SUDEP

SECTION 8

DATE ASSESSMENT COMPLETED:

ASSESSMENT REVIEW DATE:

Clinic Date

ASSESSMENT COMPLETED BY: (Signature)

NAME:

TITLE:

BAND:

REVIEW OF MEDICATION

DATE	MEDICATION CHANGED	NEW DOSE	RATIONAL FOR CHANGE IN MEDICATION DOSE

Appendix C: Equality Impact Assessment

For strategies, policies, procedures, processes, guidelines, protocols, tenders, services

1. Document or Process or Service Name: Learning Disability Epilepsy Service
2. EIA Reviewer (name, job title, base and contact details): Jenny Crofts - Epilepsy Specialist Nurse
3. Is it a Policy, Strategy, Procedure, Process, Tender, Service or Other? SOP

Main Aims of the Document, Process or Service
Please indicate in the table that follows whether the document or process has the potential to impact adversely, intentionally or unwittingly on the equality target groups contained in the pro forma

Equality Target Group 1. Age 2. Disability 3. Sex 4. Marriage/Civil Partnership 5. Pregnancy/Maternity 6. Race 7. Religion/Belief 8. Sexual Orientation 9. Gender re-assignment	Is the document or process likely to have a potential or actual differential impact with regards to the equality target groups listed? Equality Impact Score Low = Little or No evidence or concern (Green) Medium = some evidence or concern (Amber) High = significant evidence or concern (Red)	How have you arrived at the equality impact score? a) who have you consulted with b) what have they said c) what information or data have you used d) where are the gaps in your analysis e) how will your document/process or service promote equality and diversity good practice
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Equality Target Group	Definitions	Equality Impact Score	Evidence to support Equality Impact Score
Age	Including specific ages and age groups: Older people Young people Children Early years	Low	
Disability	Where the impairment has a substantial and long term adverse effect on the ability of the person to carry out their day to day activities: Sensory Physical Learning Mental health (including cancer, HIV, multiple sclerosis)	Low	
Sex	Men/Male Women/Female	Low	
Marriage/Civil Partnership		Low	
Pregnancy/Maternity		Low	
Race	Colour Nationality Ethnic/national origins	Low	
Religion or Belief	All religions Including lack of religion or belief and where belief includes any religious or philosophical belief	Low	
Sexual Orientation	Lesbian Gay men Bisexual	Low	

Equality Target Group	Definitions	Equality Impact Score	Evidence to support Equality Impact Score
Gender Reassignment	Where people are proposing to undergo, or have undergone a process (or part of a process) for the purpose of reassigning the person's sex by changing physiological or other attribute of sex	Low	

Summary

Please describe the main points/actions arising from your assessment that supports your decision.	
EIA Reviewer: Jenny Crofts	
Date completed: 19/6/24	Signature: 