Optimum clinical pathway: epilepsy

December 2019
Executive summary

This optimum clinical pathway for patients with epilepsy (PWE) was designed by a working group of epilepsy specialist clinicians and charity representatives (see Appendix for group membership), as part of an NHS England specialised neurology programme of work.

The group emphasises the need for PWE to be given access to a “first point of contact” with epilepsy expertise to triage care and provide local advice. The pathway is designed to keep as much care local as possible. As such, it specifies when patients need to be seen in a regional neuroscience centre and provides recommendations for step-down from tertiary and secondary services.

This pathway is expected to create efficiency savings while improving the quality of epilepsy services. Efficiency savings can be made with early diagnosis and attention to local management, both of which have been shown to reduce care costs while improving patient outcomes.

With current models of care, there are insufficient numbers of epilepsy specialist consultants and nurses to deliver a timely service in all areas. It is therefore important that the service address barriers in patient flow through the clinical pathway. Another barrier to the optimum pathway is the inability of centres to receive, store or share video monitoring and other patient information. Improving methods of information sharing between providers will facilitate early diagnosis and join up patient care.

Key enablers of the optimum pathway include specialist networking and virtual consultation. Additionally, increased focus on data sharing or a national epilepsy register or patient portal would greatly facilitate communication between clinicians and improve patient care.
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There is wide variation in access to specialised care across England, with the percentage of spells treated in specialised centres ranging from 8.8-15.5%. There are also concerns over outcomes, with a 33% growth in the age standardised mortality rate between 2003-2014 and a 50% increase in inpatient spells with a length of stay longer than 14 days between 2015/16 and 2017/18 (1, 2). There has also been an increasing admissions cost since 2015, likely due to longer lengths of stay and increases in emergency admissions rates.

This information pack is the output of the Epilepsy Clinical Working Group’s efforts to define the optimum pathway for patients with epilepsy. The guidance outlines:

- The “optimum” pathway for patients with epilepsy from first seizure to ongoing management.
- The definition of “specialised” epilepsy care.
- A workforce model to support implementation.
- Possible efficiency savings to come out of the optimum pathway.
- Identifies barriers and provides recommendations around patient flow, information sharing and research and clinical trials.
Pathway: first seizure to diagnosis

**Good practice**
After a first suspected seizure, a patient should be referred to a first seizure service. This should involve being seen by a general neurologist, epilepsy medical specialist, or GP with epilepsy interest within 2 weeks, and receiving investigations (ECG, EEG, MRI) if indicated within another 2 weeks (3). Local networking can facilitate correct referrals earlier (see next slide).

**First seizure service**
The patient should be seen in a first seizure clinic that is directly supervised by a physician with expertise in epilepsy. Virtual consultation is possible for some follow-up appointments and for addressing acute problems, especially if a patient needs to be kept local. Expertise in epilepsy may be demonstrated by the following:
- Training and continuing education in epilepsy
- Peer review of practice
- Epilepsy must be a significant part of their clinical workload (equivalent to at least one session/week).

At diagnosis, the diagnosing physician should agree a care plan with the patient that includes the following:
- Diagnosis, including aetiology/syndrome, and identification of relevant comorbidities;
- Antiepileptic drug treatment and any planned or ongoing changes;
- Seizure management plan with mortality risk communication and review;
- First point of contact and place of safety;
- Rescue medication plan, where indicated;
- Recommendations and signposting for independent support services; and
- Practical and/or psycho-social self-management actions agreed with patient, with progress review plan that allows for additional support to be provided as needed.
Pathway: treatment and ongoing management

Good practice

1. A good epilepsy service will provide a patient with a “first point of contact” (FPOC)

A patient’s FPOC will be named in their care plan (see Appendix 1 for more detail). The FPOC should have clinical expertise in epilepsy, typically an epilepsy specialist nurse or other suitably qualified healthcare professional. Once a patient is diagnosed with epilepsy and known to a local service, they will be able to contact their first point of contact to triage necessary care (4).

2. As much care as possible should be kept local.

A great deal of epilepsy care can be provided by GPs, including anti-epileptic drug (AED) prescription (on advice of a specialist), contraception and conception advice, mental healthcare, co-morbidities management, driving advice and DVLA forms (5). Referrals to secondary and tertiary care should only be made as needed.

A patient should be referred to tertiary care if they experience unacceptable seizure control despite appropriate management (i.e. has failed 2 anti-epileptic drugs), or if there is uncertainty regarding diagnosis or classification. A specialist may revisit diagnosis, classify the epilepsy, consider surgery, consider alternative treatments and/or additional investigations to aid syndromic classification, analyse comorbidities and manage expectations.

Step-down from tertiary service should occur as soon as possible. Currently, a patient may be kept unnecessarily in a tertiary service because tertiary specialists or patients lack confidence in secondary neurology service to provide adequate care. Similarly, secondary care or patients may lack confidence to share care with primary care. Strengthening networks by increasing local knowledge about alternatives to specialist care, and supporting efficient communication pathways between services (e.g. where there are general neurologists with epilepsy competency in a DGH) could help move patients closer to home.

Secondary care functions include the following:

- Psychological support, links with ‘liaison psychiatrists’ embedded in secondary care hospitals who have specialist knowledge of the impact of physical health issues on mental health (6)
- Diagnosis review
- Initiating AED prescription
- Linked services (e.g. maternity, LD, cardiology)
- Liaison psychiatry support
- Psychological support
- Clinical trials
Pathway: defining specialised epilepsy service

While the majority of epilepsy care can be provided at primary and secondary levels, there are some services that must be provided in a specialised centre, and some patient groups more likely to need specialised care.

Patient groups that may require specialised care or specific service models:

❖ Learning disability (this document uses the term “learning disability” in line with NHS England commissioning practice, but does not differentiate between learning and intellectual disability)
❖ Maternity
❖ Transition
❖ Elderly

Elements of specialised care: tertiary
Tertiary services are provided by all specialised centres and are not available at district general hospitals.

- 3T MRI and other advanced imaging reported by a neuroradiologist
- Neuropsychiatry and neuropsychology services
- Video EEG Telemetry service
- Research and clinical trials
- Surgery (typically temporal lobectomy, lesionectomy)
- Vagal nerve stimulation (VNS)
- Decision making and initializing non-standard medical therapies needing specialist support (e.g. ketogenic diet, cannabidiol (CBD))
- Neurogenetics

Elements of specialised care: quaternary
Quaternary services are considered ‘super specialised’ and are only provided at some specialised centres.

- Invasive video EEG telemetry (stereo, depths, grids)
- Everolimus
- Single-photon emission computed tomography (SPECT)
- Positron emission tomography (PET) scan
- Complex surgical resections
- Capacity for long admissions for complex cases, e.g. Non Epileptic Attack Disorder (NEAD), LD and behaviour
Pathway: efficiency savings

Early diagnosis
This pathway provides multiple recommendations to facilitate early diagnosis of epilepsy. Early diagnosis of epilepsy has been shown to lead to efficiency savings by getting patients on the correct treatment early. In a study by the European Project, economic modelling estimates savings from early diagnosis of £7,300 per person plus a 1.069 QUALY increase over 70 years. The study attributes cost savings to speed at which patients are seen by a specialist and the effectiveness of specialist treatment (7).

Attention to patient management
This pathway highlights the importance of a local first point of contact for people with epilepsy, to provide clinical advice and triage appropriately. It is expected that this will help PWE manage their conditions locally and thus reduce cost through preventing unnecessary presentation at emergency services.

A similar model has been proposed in the Norfolk epilepsy community service. The business case describes how the service was able to increase WTE ESNs from 1.6 in 2016 to 4.5 in 2018, due to savings gained from decreased DNA rates, A&E attendances and outpatient appointments (8).
**Patient flow**

With current models of care, there are insufficient numbers of epilepsy specialist consultants and nurses to deliver a timely service in all areas. It is therefore important that the service address barriers in patient flow through the clinical pathway.

<table>
<thead>
<tr>
<th>Barrier</th>
<th>Recommendation</th>
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| The first barrier for patients with epilepsy is ‘getting in the front door’. Only half of possible first seizure presentations to emergency departments are referred to a seizure and/or neurology clinic, and first seizures may not be prioritised over other less serious presentations. A GP also may not see a patient who has been admitted to an emergency service for a seizure, and pathways to first seizure services may not be clear. | ❖ Clear referral guidelines  
❖ GP education programmes |
| Electronic referral systems are inadequate and fail to direct GPs to the correct clinics, and there is often inadequate triaging system in hospitals. | ❖ The system should be overhauled to achieve a system that is managed under a two week rule, and facilitates referral to first point of contact for patients known to service. |

**Geography**

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| ❖ Teleconferencing and virtual consultation  
❖ Network of specialists linked virtually, operating in the community |

| Unclear definitions of who is responsible for patients when they leave service | ❖ Clear referral guidelines |

**Cross-cutting recommendation: support for self management**

Access to online self management programmes and support groups will help patients navigate the service.

Self-monitoring devices: If these were more widely used or promoted by clinicians they could help people with epilepsy improve self-management, and encourage appropriate engagement with services when a patient’s epilepsy worsens – helping to avert crisis, e.g. A&E admissions or death.

❖ Apps to help patients navigate the service.

❖ Apps to help self-manage condition in between appointments (e.g. charity apps with seizure diaries, or the risk self-monitoring app).
Alternate workforce models

Case study: St George’s NHS Foundation Trust

Actors and workforce

<table>
<thead>
<tr>
<th>Tertiary centre</th>
<th>Linked DGH services</th>
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<tbody>
<tr>
<td>▪ 3.6 WTE consultant neurologists with epilepsy special interest</td>
<td>▪ 6 DGHs in southwest London</td>
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<tr>
<td>▪ 0.2 WTE Associate Specialist</td>
<td>▪ One named consultant at each DGH with special interest in epilepsy</td>
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<tr>
<td>▪ 0.5 WTE Neuropsychologist</td>
<td>▪ Ideally at least one epilepsy nurse specialist</td>
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<tr>
<td>▪ 2.0 WTE Epilepsy Nurse Specialists</td>
<td></td>
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<tr>
<td>▪ Input from 2 consultant neurosurgeons</td>
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<tr>
<td>▪ Neuropsychiatry service</td>
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<tr>
<td>▪ Rotating specialist trainee</td>
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<td>▪ Secretarial support</td>
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Responsibilities

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<th>Tertiary management</th>
<th>Surgery evaluations &amp; MDT. Complex case MDT:</th>
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<td></td>
<td>▪ Epilepsy leads from tertiary centre and each DGH can bring patients.</td>
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<td></td>
<td>▪ Required for CBD, Everolimus, genetic testing.</td>
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<td></td>
<td>Advice as needed when referred by epilepsy lead.</td>
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<td></td>
<td>Development regional pathways, policies, information leaflets.</td>
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| DGH epilepsy lead | Management of complex cases at DGH, with the option to bring patients to the Complex Case MDT. |
|                  | Gives advice to DGH general neurologists on epilepsy care. |
|                  | Development of local pathways, policies, leaflets. |

| Local management | All ongoing medical care for PWE. |

All group management meeting every 2-3 months
Website with guidance documents

Context
Barriers and enablers
Pathway map
Clinical guidance
Information sharing

Improving methods of information sharing between providers will facilitate early diagnosis and join up patient care.

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<tr>
<th>Barrier</th>
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<tr>
<td>Lack of standard protocol on imaging.</td>
<td>❖ Integrated Electronic Health Records between providers</td>
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<tr>
<td>No system for data sharing.</td>
<td>❖ A standardised epilepsy database, preferably with video storage capability, would be incredibly useful for clinical research.</td>
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<tr>
<td>Blockages to video sharing across Trusts slows diagnosis.</td>
<td>❖ Video sharing between patients and trusts, and between Trusts ❖ Cloud encrypted data transfer service</td>
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Video sharing
This document recommends enabling video sharing between patients and carers and their Trust, and between Trusts. Videos of events and seizures are vital diagnostic tools in epilepsy. As such, enabling video sharing is essential for patient care and can save time and money through avoiding diagnostic delay and unnecessary investigations. Enabling timely diagnosis will lead to better outcomes for patients and provide opportunity to invest funds elsewhere, e.g. specialist nurses and clinical research.
Access to research and clinical trials

Investment in research and clinical trials is necessary to continue to improve epilepsy treatment, and there is evidence that there is insufficient attention to neurology research and clinical trials in England. A 2015 survey by the Neurological Alliance found that 20.7% (n=1,209) of respondents had accepted an opportunity to take part in a clinical or research study and 59.1% (n=3,461) of respondents had not been offered the opportunity to take part in a clinical or research study but would be interested in doing so (9). Public funding for health research has increased over the last 10 years but funding for neurology is down proportionately 2.5% (10).

The epilepsy clinical working group recommends the following to address barriers to research and clinical trials for epilepsy:

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| Lack of capacity and incentives for Trusts to enable clinicians to participate in research. The main barrier is lack of time given heavy clinical workload in job plans. | ❖ Identify and free up capacity.  
❖ Joined up epilepsy registry/database that is linked to routine clinical care.  
❖ Clinician and patient partnerships with epilepsy organisations to improve access to funding and PPI support for projects. |
| Inadequate networks. | ❖ Establish networks to build and deliver research programmes.  
❖ Horizon scanning to identify research opportunities. |
| Bias toward biomedical research. | ❖ Forum for clinicians interested in health services and epilepsy. |
Map of the optimum clinical pathway for epilepsy: flow

First seizure

Self referral (previous diagnosis, without established local service)

Self referral (for patients already known to a service)

INDEPENDENT SERVICE
- Local support groups
- Charities

Transition

ED/GP ASSESSMENT
- If suspected first seizure or new onset epilepsy, triage to first seizure service
- Previous diagnosis, refer to First Point of Contact (within 4 weeks)

SECONDARY MANAGEMENT
- Diagnosis review
- Drug prescription
- Linked services (e.g. maternity, LD, cardiology)
- Liaison psychiatrist
- Psychologist
- Clinical trials

COMMUNITY CARE
- Pharmacist
- Midwifery
- OTs
- Local mental health services
- Nursing home care

FIRST SEIZURE SERVICE
- Diagnosis made by consultant with epilepsy expertise
- Care plan agreed with patient
- Direct to First Point of Contact

PRIMARY CARE MANAGEMENT
- Care plan management
- AED prescribing

FIRST POINT OF CONTACT
- As defined by care plan
- Triage to appropriate service

STEP-DOWN UNACCEPTABLE SEIZURE CONTROL
- Unacceptable seizure control despite appropriate management or uncertainty re diagnosis or classification

DIAGNOSTIC UNCERTAINTY

SPECIALISED TREATMENT
- Diagnostic review
- Surgery
- VNS
- Telemetry
- Research and clinical trials
- Neuropsychology
- Specialist MDT
- Care plan agreed with patient

QUATERNARY SERVICE

STEP-DOWN SERVICE REQUIRED

Patient feedback collected and used at every stage
Clinical guidance to be considered alongside the pathway

Prescribing anti-epileptic drugs for people with epilepsy and learning disability

People with learning disability (LD) have higher prevalence of epilepsy than the general population, have higher levels of comorbid mental and physical disorders, and face greater barriers communicating their needs and wishes. This, coupled with greater likelihood of being resistant to treatment, leads to higher mortality rates for people with LD. Prescribing anti-epileptic drugs to people with LD can be difficult, due to LID patients being more susceptible to, and less able to communicate, side effects of drugs. This group would like to refer to the Royal College of Psychiatrists’ (2017) report, *Prescribing anti-epileptic drugs for people with epilepsy and intellectual disability*, for prescribing guidance for epileptic patients with LD, as well as Watkins et al.’s (2019) report, *Quality improvement in the management of people with epilepsy and intellectual disability: the development of clinical guidance* (11, 12).
Appendix 1. Referral pathways for the first point of contact

First seizure
- Clinic
  - ESN
  - Neurologist
  - Expertise in epilepsy
  - Local secondary care
  - Cardiology, neuroradiology, neurophysiology, psychology, genetics, oncology etc.

Transition from paeds
- Clinic
  - ESN
  - Neurologist
  - Expertise in epilepsy
  - Local secondary care
  - Cardiology, neuroradiology, neurophysiology, psychology, genetics, oncology etc.

Patient self-referral (post diagnosis)
  - GP/primary care
  - CLDT joint working
  - Support/service for NEAD
  - Epilepsy first point of contact will provide:
    - Planned face to face reviews
    - Planned telephone/skype reviews
    - Urgent reviews – hot clinics, telephone, Skype, text, email etc.
    - Joint pregnancy clinics/care

Tertiary centre
- Surgery
- VNS
- Dietary
- Research
- Specialist MDT, e.g. tuberous sclerosis, mitochondrial disease

Advice as required
  - For advice and specific questions, e.g. diagnostic doubt, surgery pathway
  - Escalation as required, e.g. breakthrough seizures

Cardiology, neuroradiology, neurophysiology, psychology, genetics, oncology etc.
## Appendix 2. Clinical working group membership

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<thead>
<tr>
<th>Name</th>
<th>Profession</th>
<th>Organisation</th>
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<tbody>
<tr>
<td>Tony Marson</td>
<td>Workstream clinical lead, Consultant neurologist</td>
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<td>Rohit Shankar</td>
<td>Consultant Developmental Neuropsychiatrist</td>
<td>Cornwall Partnership NHS FT</td>
</tr>
<tr>
<td>Melissa Maguire</td>
<td>Consultant Neurologist</td>
<td>Leeds Teaching Hospitals</td>
</tr>
<tr>
<td>Rhys Thomas</td>
<td>Consultant Neurologist</td>
<td>Newcastle University</td>
</tr>
<tr>
<td>Dougall McCorry</td>
<td>Consultant Neurologist</td>
<td>University Hospitals Birmingham</td>
</tr>
<tr>
<td>Hannah Cock</td>
<td>Consultant Neurologist</td>
<td>St George’s University Hospital NHS FT</td>
</tr>
<tr>
<td>Mark Manford</td>
<td>Consultant Neurologist</td>
<td>Cambridge University Hospitals</td>
</tr>
<tr>
<td>Khalid Hamandi</td>
<td>Consultant Neurologist</td>
<td>Cardiff University</td>
</tr>
<tr>
<td>Phil Tittensor</td>
<td>Consultant Nurse for the Epilepsies</td>
<td>ESNA, Royal Wolverhampton</td>
</tr>
<tr>
<td>Sammy Ashby</td>
<td>Deputy Chief Executive</td>
<td>SUDEP Action</td>
</tr>
<tr>
<td>Julie Riley</td>
<td>Divisional Director Neurology</td>
<td>Walton Centre</td>
</tr>
<tr>
<td>Angie Pullen</td>
<td>Epilepsy Services Manager</td>
<td>Epilepsy Action</td>
</tr>
<tr>
<td>Jon Dickson</td>
<td>GP, Senior Clinical Lecturer</td>
<td>Sheffield University</td>
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Glossary of terms

C
Cannabidiol (CBD)
Cannabis derivative thought to have anti-epileptic effect in Dravet Syndrome and Lennox-Gastaut Syndrome. NICE Guidance expected October 2019.

Complex surgical resections
Surgical procedures to remove areas of the brain identified as causing seizures.

E
Electroencephalogram (EEG)
A recording of electrical brain activity in which small electrodes are attached to the scalp. An EEG is usually performed by the team in a neurophysiology department in a hospital.

Everolimus
Medicinal treatment for tumours and for focal onset seizures caused by tuberous sclerosis complex (TSC).

Invasive video EEG telemetry
A recording of seizures using video and EEG including electrodes placed into the brain or a grid of electrodes over the surface of the brain.

K
Ketogenic diet
A diet high in fats and low in carbohydrates, which can reduce seizures although it is no currently recommended by NICE.

N
Neurogenetics
Study of the generic causes of neurological diseases.

Non Epileptic Attack Disorder (NEAD)
A disorder in which patients experience seizures, which have a psychological cause, as apposed to epileptic seizure that are due to abnormal electrical activity.

P
Positron emission tomography (PET) scan
Scans that produce images of the brain by detecting radiation given off by a radiotracer injected into a vein in an arm.

S
Single-photon emission computed tomography (SPECT)
A scan that measures blood flow in the brain, using a radioactive substance injected into the arm followed by a computed tomography (CT) scan. Measuring blood flow can help detect the origin of a seizure.

V
Video EEG Telemetry (vEEG)
A vEEG involves having an EEG whilst being videoed at the same time. Patients are often admitted to hospital for 5-7 days for this investigation.

Vagal nerve stimulation (VNS)
An implanted device that sends small electrical pulses to the vagus nerve in the neck. Impulses travel up to the brain to reduce seizures.
References


2. Secondary User Services (SUS) database


4. This recommendation is supported by NICE Quality Standard 5 on epilepsy specialist nurses. https://www.nice.org.uk/guidance/qs26/chapter/quality-statement-5-epilepsy-specialist-nurse.


