

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.

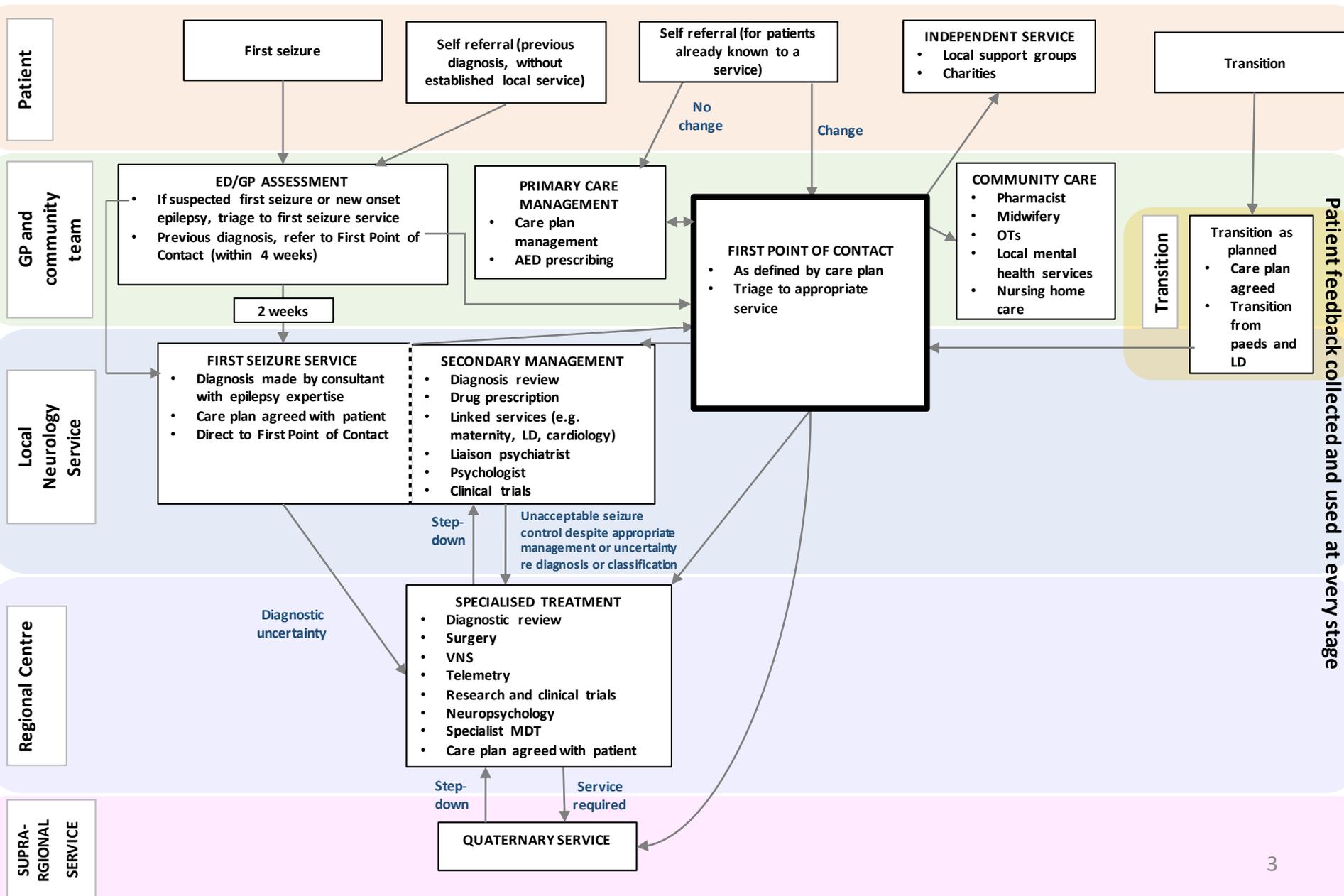
The group emphasises the need for PWE to be given access to a “first point of contact” with epilepsy expertise to triage care and provide local advice. The pathway is designed to keep as much care local as possible. As such, it specifies when patients need to be seen in a regional neuroscience centre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

Executive summary



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Context

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).

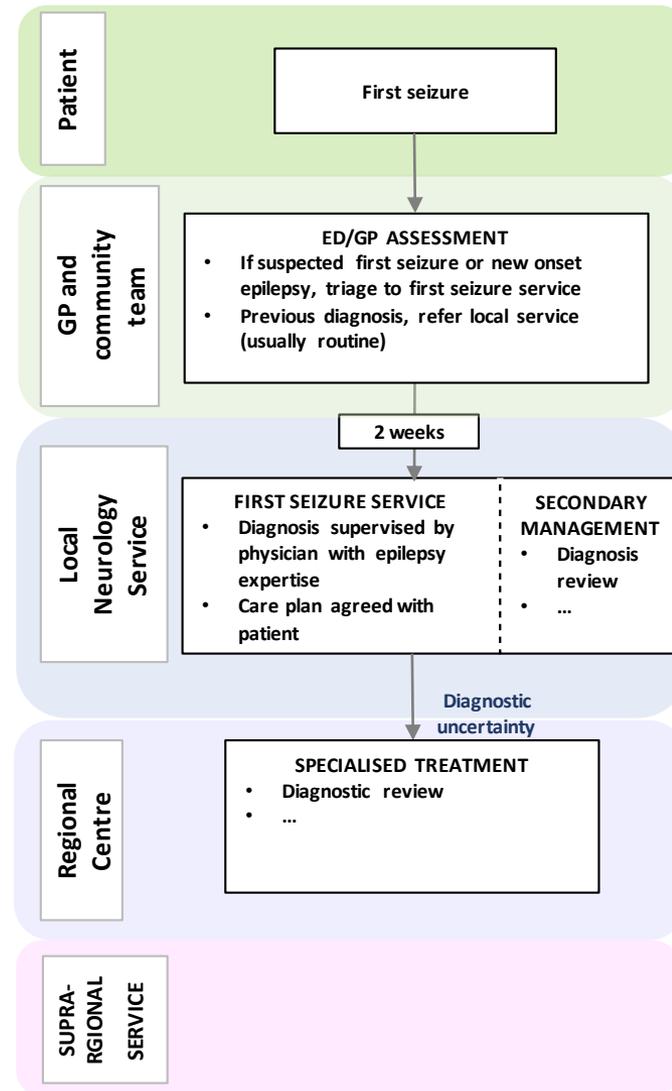
First seizure service

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.

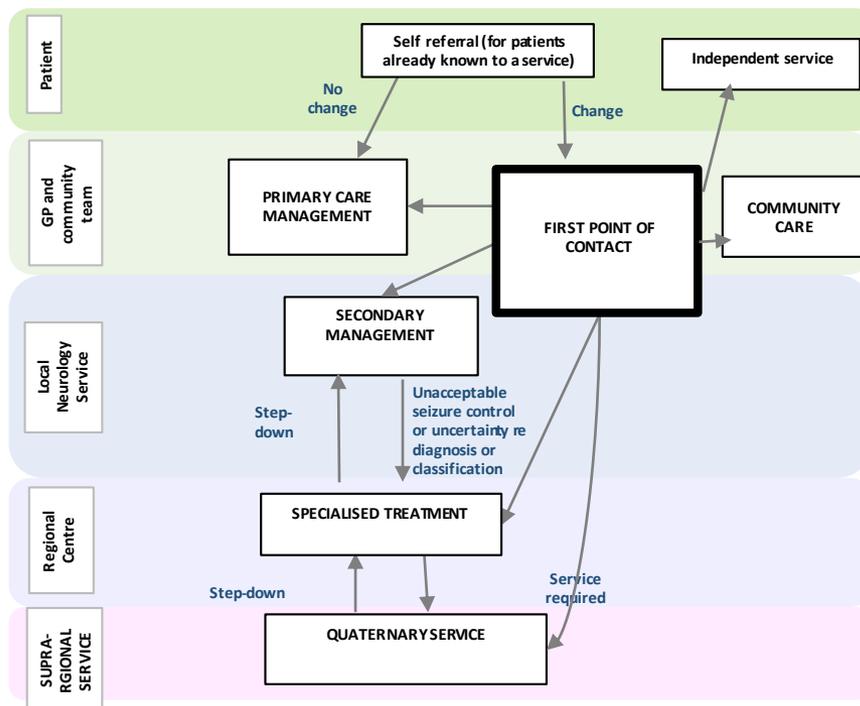
A great deal of epilepsy care can be provided by GPs, including anti-epileptic drug (AED) prescription (on advice of a specialist), contraception and conception advice, mental healthcare, co-morbidities management, driving advice and DVLA forms (5). Referrals to secondary and tertiary care should only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

Barrier	Recommendation
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.	<ul style="list-style-type: none"> ❖ 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.	<ul style="list-style-type: none"> ❖ 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	<ul style="list-style-type: none"> ❖ 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	<ul style="list-style-type: none"> ❖ 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

Tertiary centre	Linked DGH services
<ul style="list-style-type: none"> ▪ 3.6 WTE consultant neurologists with epilepsy special interest ▪ 0.2 WTE Associate Specialist ▪ 0.5 WTE Neuropsychologist ▪ 2.0 WTE Epilepsy Nurse Specialists ▪ Input from 2 consultant neurosurgeons ▪ Neuropsychiatry service ▪ Rotating specialist trainee ▪ Secretarial support 	<ul style="list-style-type: none"> ▪ 6 DGHs in southwest London ▪ One named consultant at each DGH with special interest in epilepsy ▪ Ideally at least one epilepsy nurse specialist

Responsibilities

Tertiary management	Surgery evaluations & MDT. Complex case MDT: <ul style="list-style-type: none"> ▪ Epilepsy leads from tertiary centre and each DGH can bring patients. ▪ Required for CBD, Everolimus, genetic testing. Advice as needed when referred by epilepsy lead. Development regional pathways, policies, information leaflets.	All group management meeting every 2-3 months Website with guidance documents
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.	

Information sharing

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

Barrier	Recommendation
Lack of standard protocol on imaging.	❖ Integrated Electronic Health Records between providers
No system for data sharing.	❖ A standardised epilepsy database, preferably with video storage capability, would be incredibly useful for clinical research.
Blockages to video sharing across Trusts slows diagnosis. <ul style="list-style-type: none"> ▪ Trust rules ▪ Patients unable to send videos into Trusts (files too big to email, cloud services blocked or insufficiently secure) ▪ Too many discrete systems across Trusts (NHS-wide issue) ▪ Platforms with video sharing have extra cost 	<ul style="list-style-type: none"> ❖ Video sharing between patients and trusts, and between Trusts ❖ Cloud encrypted data transfer service

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.

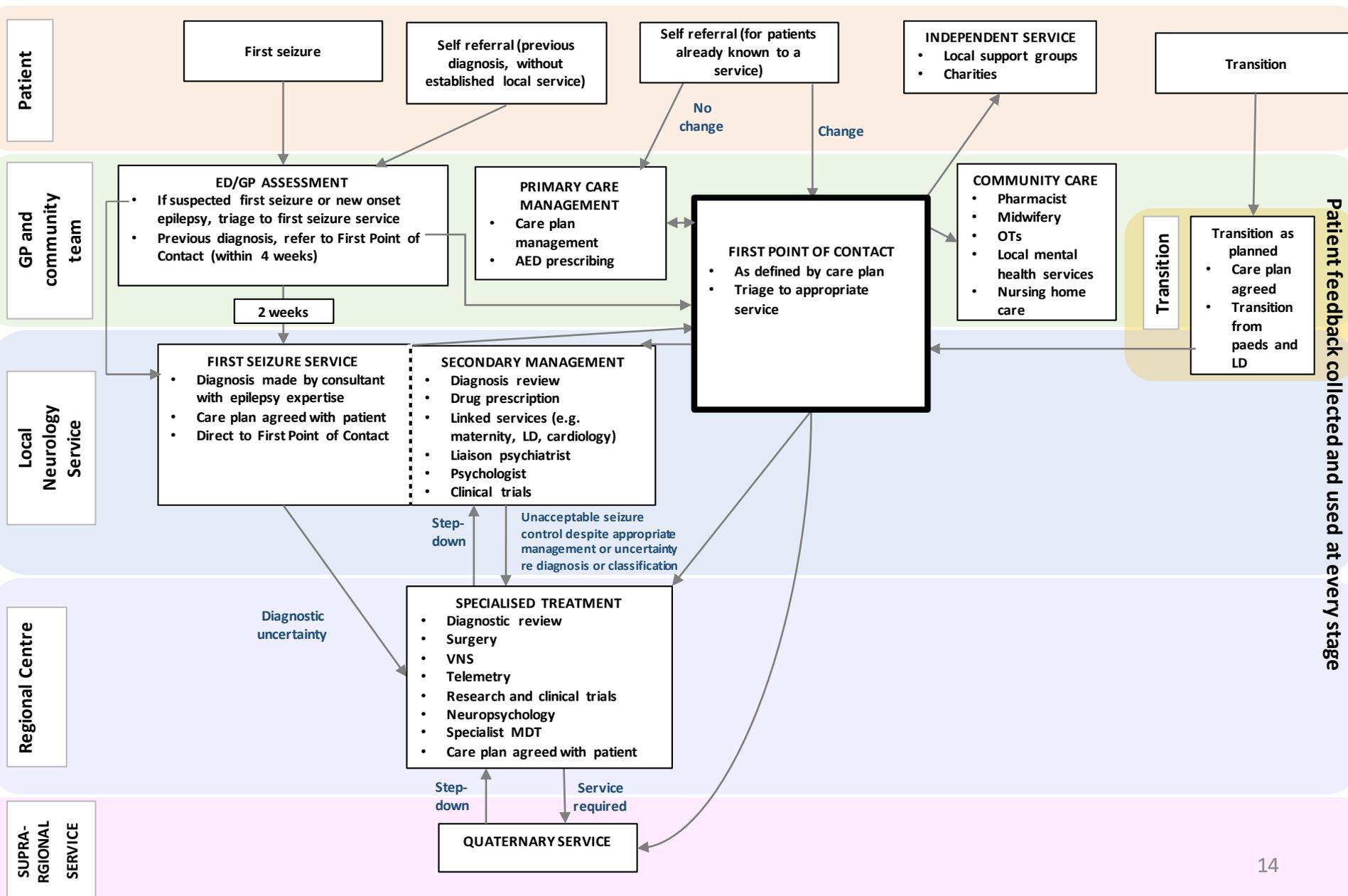
Access to research and clinical trials

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:

Barrier	Recommendation
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.	<ul style="list-style-type: none"> ❖ 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.	<ul style="list-style-type: none"> ❖ Establish networks to build and deliver research programmes. ❖ Horizon scanning to identify research opportunities.
Bias toward biomedical research.	<ul style="list-style-type: none"> ❖ Forum for clinicians interested in health services and epilepsy.

Map of the optimum clinical pathway for epilepsy: flow



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).

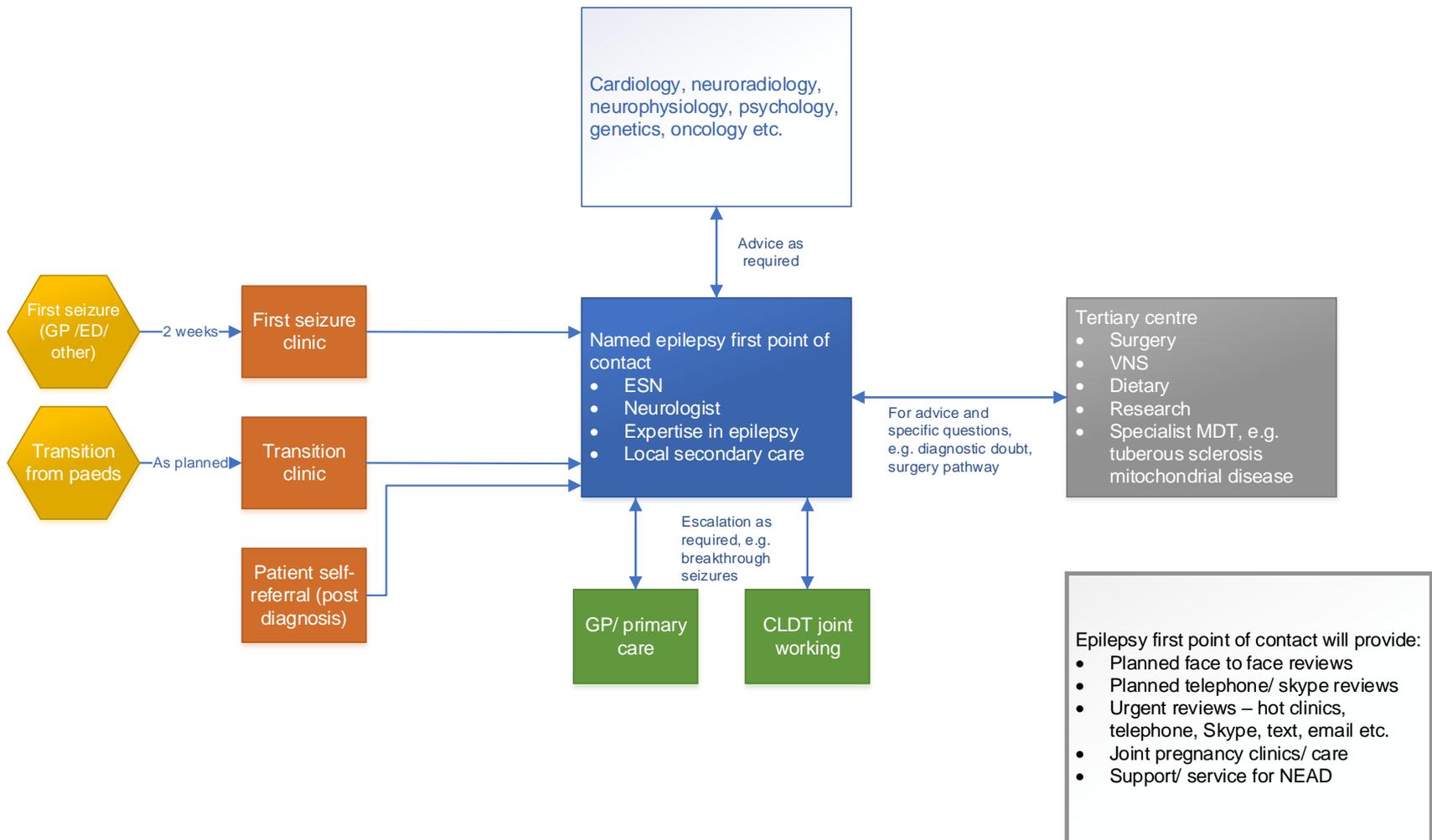


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Prescribing anti-epileptic drugs for people with epilepsy and intellectual disability

COLLEGE REPORT

Appendix 1. Referral pathways for the first point of contact



Appendix 2. Clinical working group membership

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

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).

I

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 not currently recommended by NICE.

N

Neurogenetics

Study of the genetic causes of neurological diseases.

Non Epileptic Attack Disorder (NEAD)

A disorder in which patients experience seizures, which have a psychological cause, as opposed 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

1. Public Health England. (2018). *Deaths associated with neurological conditions in England 2001 to 2014*. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/683860/Deaths_associated_with_neurological_conditions_data_analysis_report.pdf.
 2. Secondary User Services (SUS) database
 3. National Institute for Health and Care Excellence (NICE). *NICE Pathways: Diagnosing and classifying epilepsy*. <https://pathways.nice.org.uk/pathways/epilepsy#path=view%3A/pathways/epilepsy/diagnosing-and-classifying-epilepsy.xml&content=view-index>
 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>.
 5. Dickson, J. (2018). Importance of GPs for people with epilepsy: a personal view. *Epilepsy Professional*. Available at: <https://store.epilepsy.org.uk/collections/membership/products/epilepsy-professional-magazine>.
 6. Royal College of Psychiatrists. (2017). *Management of epilepsy in adults with intellectual disability*. Available at: <https://www.rcpsych.ac.uk/improving-care/campaigning-for-better-mental-health-policy/college-reports/2017-college-reports/management-of-epilepsy-in-adults-with-intellectual-disability-cr203-may-2017>.
 7. Mahon et al. 2019. The cost effectiveness of evidence-based care versus current care for individuals with epilepsy in Europe: an economic analysis. *Working paper*.
 8. Bangrove, J. (2019). Epilepsy nurse model: Expansion of the Norfolk adult community epilepsy specialist nurse (ESN) team. *Epilepsy Professional*. Available at: <https://www.epilepsy.org.uk/involved/join/member-types/professional/epilepsy-professional-magazine>.
 9. Neurological Alliance. (2015). *The invisible patients: Revealing the state of neurology services*. Available at: https://www.neural.org.uk/resource_library/invisible-patients/.
 10. UK Clinical Research Collaboration. (2015). *UK Health Research Analysis 2014*. Available at: <http://www.ukcrc.org/wp-content/uploads/2015/08/UKCRCHealthResearchAnalysis2014-WEB.pdf>.
 11. Royal College of Psychiatrists. (2017). *Prescribing anti-epileptic drugs for people with epilepsy and intellectual disability*. Available at: <https://www.rcpsych.ac.uk/improving-care/campaigning-for-better-mental-health-policy/college-reports/2017-college-reports/prescribing-anti-epileptic-drugs-for-people-with-epilepsy-and-intellectual-disability-cr206-oct-2017> (Accessed 11th April 2019).
 12. Watkins L., O'Dwyer, M., Kerr, M., Scheepers, M., Courtenay, K. & R. Shankar (2019). Quality improvement in the management of people with epilepsy and intellectual disability: the development of clinical guidance, *Expert Opinion on Pharmacotherapy*, DOI: 10.1080/14656566.2019.1695780
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