



# London Epilepsy Standards for Children and Young People

Promoting integrated, holistic care for all children  
and young people affected by epilepsy

May 2018

## About this document

These standards bring together a number of children's standards into one document. We would like to acknowledge the work of the numerous organisations referenced throughout.

These standards have been developed through Healthy London Partnership's Children and Young People's Epilepsy Standards Group and have since been reviewed by members of Healthy London Partnership's Clinical Leadership Group. There has been consultation with external partners and national bodies. This is a document that will change according to published national and statutory guidance and can be amended accordingly.

This document was created in partnership with Young Epilepsy.



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# A) Guide to Holistic, integrated epilepsy care

## 1 Introduction

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### 1.1 Purpose

Healthy London Partnership formed in April 2015. It has been working across health and social care, and with the Greater London Authority, Public Health England, NHS England, London's councils, clinical commissioning groups, and Health Education England. We have united to amplify the efforts of a growing community of people and organisations that believe it is possible to achieve a healthier global city by 2020. Healthy London Partnership is focused on transformation programmes, one of which is the Children and Young People's (CYP) Programme. Our vision is for an integrated system for health and care services, which promotes health and well-being and can be easily navigated by children, their families and health professionals to achieve the best outcomes.

### 1.2 Audience

The document is aimed at commissioners and providers of epilepsy healthcare services for children and young people. Section A of the document is also intended for young people and families affected by epilepsy, providing an overview of the roles and responsibilities of those who commission and provide care.

This document has brought together information and standards for epilepsy healthcare into one place to enable the effective commissioning of services that meet these required minimum standards. Providers can use these standards to undertake a self-assessment of their ability to deliver the required quality care for children. They can be used to validate, challenge, to quality assure and improve outcomes for children and young people with epilepsy.

### 1.3 Overarching principles of these standards

#### Clinical pathway

- 1) CYP with suspected seizures should be seen promptly and investigated appropriately, in accordance with current NICE guidance
- 2) CYP with epilepsy should be referred for tertiary care assessment in accordance with NICE guidance
- 3) Where warranted, anti-epileptic drug treatment should be commenced in line with NICE guidance or other up-to-date, evidence-based practice. Appropriate formulations should be considered in order to optimise concordance.
- 4) CYP with epilepsy should receive at least annual review, or sooner if clinically indicated, in accordance with NICE guidance.

## Description and documentation

- 5) CYP with epilepsy should have their seizure/event types described accurately in documentation
- 6) CYP with epilepsy should have their epilepsy classified using the latest ILAE multi-axial classification and, where appropriate, a precise electro clinical syndrome
- 7) CYP with epilepsy should have an appropriate individualised care plan, drawn up in conjunction with the young person/family, and input from any other relevant professionals providing care.

This should include what to do in the event of a seizure (especially prolonged seizures), as well as other tailored advice for that individual young person. It should be reviewed annually (or sooner if changes are warranted).

- 8) Permission should be sought to share documentation with the child/young person's school/college and other relevant professionals (e.g. social worker, mental health professional), to encourage joined-up care.

## Holistic impact of epilepsy

- 9) CYP with epilepsy should have the functional impact of their epilepsy (including mental health, wellbeing, education and quality of life) regularly assessed and documented, regardless of seizure control.
- 10) Appropriate safety and lifestyle advice should be given to every CYP with epilepsy, both at diagnosis and also at regular intervals.
- 11) Every interaction with a CYP with epilepsy should be appropriately inclusive and accessible, based on the individual's needs.

## Support

- 12) CYP with epilepsy should have access to advice from a trained epilepsy specialist nurse within 24 hours or, if out-of-hours, on the next working day.
- 13) Every CYP with epilepsy should be offered appropriate mental health, behavioural and cognitive assessment, by an appropriately trained professional, independent of seizure activity.
- 14) CYP with epilepsy should be signposted to available self-management and peer support opportunities wherever possible.
- 15) Shared decision-making within consultations, and methods to ensure CYPF influence on services, should be encouraged and promoted.
- 16) CYP with epilepsy should have access to structured transition planning towards adult services, as early as possible

## 1.4 Background and case for change

Epilepsy is one of the common major long-term conditions (LTCs) affecting children and young people (CYP), and the major neurological condition in this age group. According to the best current estimates, 63,400 children and young people aged 18 and under have epilepsy in the UK.

- In London this equates to about 2,000 children and young people (1%).

This means that:

- the average primary school in London will have approximately 1-2 pupils with epilepsy
- the average secondary school 4-5 pupils with epilepsy
- special needs schools are likely to have in excess of these numbers.

This document has been compiled because of increasing evidence that outcomes for CYP with epilepsy are sub-optimal. For example, according to a range of leading sources:

- Inadequate management has been demonstrated in almost 50% of investigated cases.
- 24-59% of studied deaths in young people with epilepsy have been shown to have been potentially avoidable.
- The proportion of UK paediatric services with access to an epilepsy specialist nurse is only 59%.
- Mental health co-morbidities are 5 times more common in CYP with epilepsy than in the general population.
- Up to 95% of school-aged children with epilepsy have significant difficulties with learning or behaviour.
- 60% of school children with epilepsy have a behavioural disorder.

### Why are outcomes sub-optimal?

The reasons for this conclusion are diverse, but can be grouped into several main themes:

- *Misdiagnosis* has been, and remains, a major concern

It is certainly true that epilepsy is inherently a difficult condition to accurately diagnose. It is also the case that, unlike some conditions, there is not any one test by which epilepsy can be diagnosed. Even with these in mind, however, the rate of *overdiagnosis* is unacceptably high. One study found that up to 40% of CYP referred to specialist clinics eventually transpired not to have the condition, with overtreatment with anti-epileptic drugs an inevitable consequence for some. Meanwhile, *undertreatment* is also a significant problem, with estimates that up to 70% of people with epilepsy could be free of seizures if appropriately managed.

- *Poor communication* has been identified as a major contributory factor in many seminal reports on epilepsy care.

This refers both to issues with communication between professionals caring for children and young people with epilepsy and, importantly, between professionals and families.

- *Variation in care* continues to be an issue.

A well-known enquiry reported that systemic failings are often to blame, rather than issues with individual practitioners. Specific issues have been highlighted with access to appropriate care and utilisation of resources.

- *Fragmentation of services* plays a big role in perpetuating poor care.

Many sectors provide important care for CYP, including health, mental health, social care and education. However, this means that professionals looking after the same child or young person often work in separate organisations. This fragmentation in care - linked to poor communication – often results in uncoordinated plans for individual young people. For the same reasons, it is rare for any kind of integrated strategy to be in place over a population area, to aid improved service planning and provision.

## What has been done to date to improve care?

In response to some of these acknowledged challenges, several initiatives have been established:

- Training:

The British Paediatric Neurology Association (BPNA) established a clinical model now familiar to CYPF and practitioners, working across primary, secondary, tertiary and quaternary healthcare. The aim of this was to improve access to specialists and appropriate investigations, to better identify which patients were suitable for non-medical interventions. The model prioritised the invaluable role of epilepsy specialist nurses (ESN) in care, and led to the creation of the ‘paediatrician with an expertise in epilepsy’. In addition, a formal training programme - the Paediatric Epilepsy Training (PET) courses – was founded, becoming the gold standard in clinical epilepsy training.

- Guidelines and specifications:

National guidelines for childhood epilepsy care were published in 2004, and are now on their second iteration, published in 2012. These provide specific clinical practice recommendations and, in the case of the NICE Quality Standard, outline what a ‘good’ service should look like. However, new therapies and an expanding evidence base have led to differences in clinical practice since their publication.

- National audit:

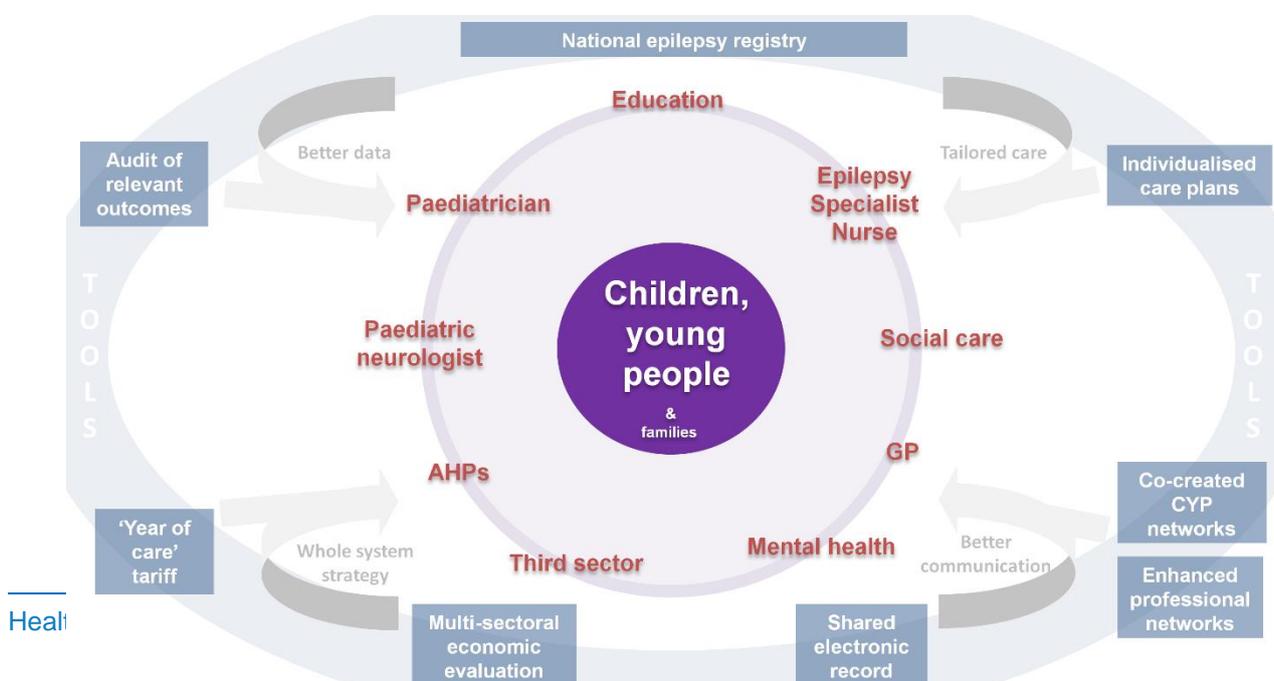
Epilepsy12 has held up a mirror to the performance of clinical epilepsy services across the UK, reporting twice since its inception, in 2012 and 2014. This data has been invaluable in providing a snapshot of service indicators and performance. This information has been available both on a national and a service level, helping to identify need for local service improvement measures. The audit is due to start the next round again in 2018, this time examining prospective data.

## Why are these standards needed?

Despite the above interventions, poor outcomes have persisted. Meanwhile, there is increasing evidence of the wider impact of epilepsy on day-to-day function.

A report from Young Epilepsy, in association with its partners (Great Ormond Street UCL Institute of Child Health, UCLPartners and Whittington Health), examined the ongoing areas of concern, by speaking with CYPF and professionals across all sectors involved in delivering care. The report identified the following persisting issues as barriers that continue to prevent good care:

- Minimal improvement in national audit data. The statistic about epilepsy specialist nurses provides a striking example: CYP in over one-third of paediatric services across the country do not have access to a nurse.
- Inherent complexity of epilepsy as a condition. Epilepsy is a heterogeneous condition, with a unique impact on each young person.
- Difficulties in navigating complex systems and services.
- Resources that are scarce and not always appropriately utilised.
- Need for improved training of professionals, within healthcare and in other sectors.
- The voice of CYPF is lacking in decision-making (both for individuals and in influencing the design and delivery of services).
- Poor communication.
- Lack of a personalised approach to care.
- Continued variation in care.
- A lack of meaningful data.



As a result, the same team proposed a model of care that takes into account the whole person and the broad impact of epilepsy on them.

## What do these standards add?

This document is intended for both CYPF and service providers as a set of *up-to-date, locally relevant* and *usable* standards, outlining:

- What are the roles and responsibilities of different professionals that provide care for CYP with epilepsy?

By understanding how the different sectors that provide epilepsy care fit together, both CYPF and professionals will find it easier to navigate a system that is acknowledged by all to be complex. Making these clearer should also help to identify and manage currently unmet needs, such as emotional and behavioural difficulties

- What can CYPF expect when they see different professionals and their teams? And what can professionals expect when they refer or signpost to other services?

By outlining what happens in a typical service, and practical principles of care within that service, CYPF will know what to expect when they are first referred, helping to reduce some of the anxiety that often happens as young people travel through what is traditionally called the “patient pathway”. Equally, this should help to empower CYPF to mention other issues that they previously did not feel would be addressed by their team.

- What should a “good” service look like?

In collating standards, this document distils a wealth of information (derived from evidence and existing guidance), into an easy-to-use set of standards against which a service can benchmark their performance.

- What impact can epilepsy have on the individual?

By acknowledging the broad impact of epilepsy, and providing information on the commonly affected areas of function, this document encourages professionals to consider such issues, and empowers CYPF to be vigilant for their impact.

Overall, this document aims to encourage *integration* across health, educational, social care and voluntary sectors, and prompt professionals to work in *partnership* with CYPF. This should lead to a truly *holistic, person-centred* approach to caring for children and young people with epilepsy, and *improving the outcomes that truly matter*.

## 1.5 What is epilepsy, and why do children and young people have epilepsy?

Epileptic seizures manifest as a transient brain dysfunction, which is broadly the result of an imbalance of excitatory and inhibitory mechanism within the network of cortical nerve cells (neurons) leading to abnormal excessive or hypersynchronous activity.

Depending on the brain areas that are involved a range of manifestations occur:

- motor: body/ limb stiffening (tonic), jerking (clonic), loss of muscle tone (atonia),
- complex motor or behavioural manifestations,
- subjective manifestations: sensory or emotional).

## Seizures that are not epilepsy

### *Provoked seizures:*

However, not all individuals that experience seizures at some point in their life have a diagnosis of epilepsy. Several acute conditions or circumstances can affect the brain resulting in a transitory increased susceptibility to generate seizures for a limited time until these have resolved or ended, for example:

- infections
- trauma
- strokes
- fever in young children (usually up to the age of 5 years)
- low blood sugar level
- hormonal or electrolyte imbalances ('provoked seizures').

### *Non-epileptic seizures:*

It is important to be aware of non-epileptic seizures (NES), which consist of changes in behaviour or consciousness and may, to an observer, resemble epileptic seizures. However, NES are not accompanied by the electrical changes in the brain seen in epilepsy. Importantly, many young people with NES also have a diagnosis of epilepsy. As such, it is important that Individualised Healthcare Plans for these CYP make clear which events are epileptic seizures (requiring emergency management as mentioned previously in this guidance), and which events are NES.

### *Seizures that are epilepsy*

Epilepsy is defined as a *disease* of the brain that manifests in the sustained susceptibility of an individual to experience unpredictable interruptions of normal brain function in the form of *unprovoked* epileptic seizures.

The taskforce of the ILAE (International League Against Epilepsy) defines epilepsy uses the following 3 concepts to define this sustained susceptibility for unprovoked seizures:

- *Recurrence of unprovoked seizures* ("At least two unprovoked (or reflex) seizures occurring more than 24 hours apart")
- *Very high risk of seizure recurrence after one unprovoked seizure* ("One unprovoked (or reflex) seizure and a probability of further seizures like the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years ")
- *Clear identification of an epilepsy syndrome* (see explanation below) – "Diagnosis of an epilepsy syndrome"

Seizures can be grossly categorised as ‘focal onset’, ‘generalised onset’ and ‘unknown onset’. ‘Focal’ and ‘generalised onset’ seizures have several subcategories (see also <https://www.ilae.org/news-and-media/news-about-ilae/new-ilae-seizure-classification> for most up to date seizure classification)

### *Causes*

Epilepsy can have many different causes, though in a significant proportion of patients, the underlying cause of the epilepsy is unknown. Those where the cause can be identified usually fall into one of the following categories:

- structural brain abnormalities: congenital (present from birth); acquired brain insults (trauma, birth trauma, strokes).
- genetic
- metabolic
- Immune (mediated process)
- Infectious

### *Classification*

Epilepsies can also be categorised into “Epilepsy Syndromes” based on details in clinical presentation (for example age of onset, seizure type) and EEG characteristics. Many specific epilepsy syndromes present at certain ages: neonatal/infantile, childhood, adolescence/adult age (see table 1 below).

Correct diagnosis of an epilepsy syndrome, and appropriate investigations into an underlying cause, is important to guide decisions about the most effective anti-epileptic medication or other therapeutic interventions. (For example, early identification of suitable candidates for epilepsy surgery). Equally, classifying the epilepsy can also help to predict the seizure outcome and identify risks for associated motor, cognitive, or behavioural impairments.

Whilst epilepsy with or without associated cognitive and behavioural impairments can be the dominant presentation, in some children and young people epileptic seizures are part of a more complex clinical presentation of neurodegenerative or metabolic disorders, which are often progressive and associated with severe sensory/motor and cognitive disabilities. These children and young people are often looked after by several specialist physicians and therapists. Communication and coordination in the care of these children is especially vital.

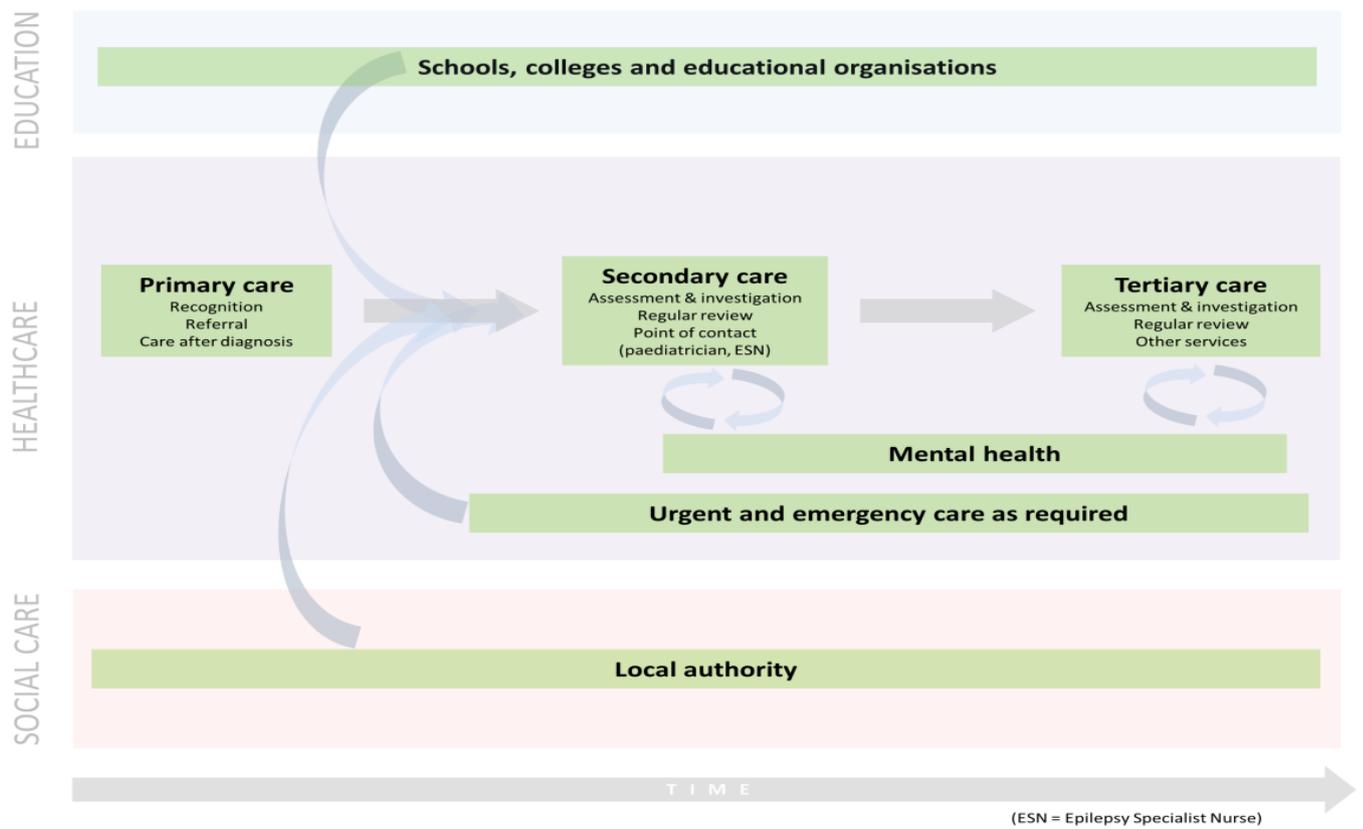
**Table 1: Epilepsy syndromes**

| <b>Age Group</b>            | <b>Epilepsy Syndromes</b>   |
|-----------------------------|---|
| <b>Neonatal / Infantile</b> | Self-limited neonatal seizures, Self-limited familial neonatal epilepsy |
|                             | Self-limited familial and non-familial infantile epilepsy               |
|                             | Early myoclonic encephalopathy  |
|                             | Ohtahara Syndrome   |
|                             | West Syndrome   |
|                             | Dravet Syndrome   |
|                             | Myoclonic epilepsy in infancy   |
|                             | Epilepsy of infancy with migrating focal seizures                       |
|                             | Myoclonic encephalopathy in non-progressive disorders                   |
|                             | Febrile seizures plus, genetic epilepsy with febrile seizures plus      |
| <b>Childhood</b>            | Epilepsy with myoclonic-atonic seizures                                 |
|                             | Epilepsy with eyelid myoclonias   |
|                             | Lennox-Gastaut Syndrome   |
|                             | Childhood absence epilepsy  |
|                             | Epilepsy with myoclonic absences  |
|                             | Panayiotopoulos syndrome  |
|                             | Childhood occipital lobe epilepsy (Gastaut)                             |
|                             | Photosensitive occipital lobe epilepsy                                  |
|                             | Childhood epilepsy with centrotemporal spikes                           |
|                             | Atypical childhood epilepsy with centrotemporal spikes                  |
|                             | Epileptic encephalopathy with continuous spike-and-waves during sleep   |
|                             | Landau-Kleffner syndrome  |
| <b>Adolescence/Adult</b>    | Juvenile absence epilepsy   |
|                             | Juvenile myoclonic epilepsy   |
|                             | Epilepsy with generalised tonic-clonic seizures alone                   |
|                             | Autosomal dominant epilepsy with auditory features                      |

|  |  |
|--|--|
|  | Other familia temporal lobe epilepsies |
|--|--|

For detailed description see <https://www.epilepsydiagnosis.org>

## 1.4 Pathway of epilepsy care



## 2 Clinical

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### 2.1 Primary and Community care

#### Recognition and involvement in diagnosing epilepsy

General practitioners (GPs) are often the first point of contact for the initial presentation of a child or young person with seizures, and for ensuring the individual is referred on for specialist opinion. Whilst a parent bringing their child may themselves suspect a seizure or seizures have occurred, it is of course important that GPs remain vigilant to the potential of different seizure types and how they may manifest. A clear history of the episode(s) is essential. If there is any suspicion that an episode may be a seizure, the child or young person must be referred on to either a paediatrician with a special interest in epilepsy, or a neurologist (depending on local pathways).

Therefore it is important for GPs:

- To keep up to date with national guidelines and recommendations around epilepsy (current NICE guidance).
- To specifically be aware of when to refer for suspected epilepsy.

#### Care after diagnosis

Whilst children and young people diagnosed with epilepsy will have their management led by specialists within secondary or tertiary care with at least annual review, (see these sections for details of their roles), GPs continue to have a crucial role after diagnosis, including:

- ensuring ongoing supply of AEDs (medication)
- monitoring for presentation of complications from epilepsy and/or from medication
- managing both pre-existing, and monitoring for new, co-morbidities and related issues
- providing support for children, young people, family and carers
- helping to facilitate transition to adult services, alongside the young person's epilepsy team, as per locally agreed pathways.

To achieve the above, the following processes can be put in place:

- Named GP to be accessible for the CYP and family/ carers in the support of continuity of care for patient.
- Call and recall system in place for medication review.
- Personalised care for each CYP with epilepsy, with use of care plan tools such as the [Royal College of Paediatric Child Health Epilepsy Passport](#) or other care plans

- Support of any additional wider needs for the children young people and families (CYPF), e.g. education, housing.
- Support of young people with epilepsy in accessing sexual health advice and contraception.
- System in place to monitor non-attendance of epilepsy clinic appointments (sometimes called DNA (did not attend) or WNB (was not brought)).
- Facilitating good communication channels with local epilepsy teams (e.g. clarifying any unclear areas of management from clinic letters).
- Ensure supply of emergency and repeat prescription for AEDs.
- Strong link with community pharmacies in case of medication supply issues.

## 2.2 Secondary Care

Children and Young People with suspected seizures present to secondary care services via one of two routes:

- referral from their primary care provider, usually their GP, or
- the Emergency Department (ED).

Whilst this structure of being assessed by a specialist in epilepsy has long been in place nationally, there can often be a delay in accessing high quality care by the right professional at the right time. For this reason, NICE has published excellent, easy-to-follow guidance. The recommendations in this section aim to address pathways of care for children and young people (CYP) with suspected or confirmed epilepsy in London according to established best practice in line with NICE.

### What is a secondary care epilepsy service in London?

A secondary care paediatric epilepsy service may be located in an acute hospital or community paediatric setting. Whilst the make-up of each service can differ, as a minimum a service consists of a Lead Paediatrician with Expertise in the Epilepsies, and an Epilepsy Specialist Nurse (ESN). They work with a team of other professionals in the acute Trust, community services and tertiary care.

Care is usually provided from a dedicated epilepsy or 'first fit' clinic. However, community paediatricians (who look after children with disabilities), may provide direct care in special schools or in community clinics. Access into the secondary care epilepsy service is from primary care or from other secondary care colleagues requesting assessment (usually from the ED).

Each service will have recommended pathways of care into specialist (tertiary) neurology services and also to CYP mental health services - which may be provided locally as a 'liaison' service, or in the community. For teenage patients approaching adulthood there should be pathways of care into adult services with clear transition arrangements in place as early on as possible.

However, there remain large variations in provision across London (and indeed the UK), especially in regard to access to ESNs, timely mental health provision and transition arrangements. All secondary care epilepsy services are required to register with the national Epilepsy 12 audit and review their service arrangements at regular intervals.

## Paediatrician with Expertise in Epilepsy

A Paediatrician with Expertise in Epilepsy:

- is a children's specialist, usually a consultant, who has undergone additional training in epilepsy
- spends a significant amount of their time per week looking after children and young people with suspected or confirmed epilepsy
- maintains their practice through regular training, plus attendance at an epilepsy network and other educational meetings and courses.

Typically there is more than one such paediatrician per trust and for some trusts they meet with other professionals within their trust or with neighbouring trusts for case discussion or peer review. They refer onwards to tertiary care when necessary as per agreed local pathways (compliant with NICE recommendations) and are expected to share information efficiently with community teams, GPs and Social Care, with prior consent from the parent or carer and patient in the case of a young person.

## Paediatric Epilepsy Specialist Nurse (ESN)

ESNs:

- are usually relatively senior paediatric nurses
- work closely with the Paediatrician with Expertise in Epilepsy
- also work with the wider community team such as school nurses, mental health professionals, community nurses, health visitors, young people's organisations, charities etc.
- are a key contact for parents, young people and professionals, providing advice and guidance

Depending on seniority, they may lead their own ESN clinics, in addition to joining the CYP clinics, with their paediatrician. They may be directly employed by an acute Trust, or by community services with links into acute Trusts, and so their scope of practice may vary. When hospital-based, ESNs are a key resource to support patients with seizures presenting to the ED and wards as well as clinics.

ESNs are usually the key to successful transition and will often lead these arrangements, with input from the paediatrician through to handover clinic at the right time. Unfortunately, despite being a 'gold standard' in epilepsy care, access to ESNs amongst services across London varies.

## Psychological Medicine

A clear link with mental health provision is essential for CYP with a diagnosis of epilepsy. Psychologists, psychotherapists and psychiatrists or other appropriately trained professionals are key to supporting CYP and their families. These may be hospital-based 'liaison' teams, or teams working within the community with outreach services into schools.

## 2.3 Outpatient Care

### Referral from primary care into secondary care for children and young people with suspected epilepsy

There should be clear, locally agreed referral pathways from primary to secondary care. Children and young people referred for suspected epilepsy to their local CYP epilepsy service should be seen within two weeks of referral, as per NICE guidelines. This generally means referring as part of an 'urgent referral' (rather than a 'standard e-referral', that may not only result in an inappropriate wait, but may also mean the CYP being seen far from their local service and appropriate community support, thus delaying the right care).

Referral pathways should take into account if the child already has a disability or neurological condition, as they may already be cared for by a community paediatrician who may be able to liaise directly and initiate investigations through their colleagues in the acute Trust.

For children and young people where there is concern that they should be seen sooner than two weeks, GPs should speak directly with the local epilepsy team or on-call paediatrician, so that assessment and appropriate investigations can be organised. Examples of such cases would be in those with frequent seizures, or in the case of infants, especially if an epilepsy such as Infantile Spasms was suspected.

### Initial assessment

Regarding the first appointment for assessment:

- This should be with a paediatrician with expertise in epilepsy, in an appropriate clinic setting (e.g. 'first fit' clinic, or 'seizure clinic').
- The appointment should be within two weeks of referral, or sooner if thought urgent.
- The consultation slot should be of adequate duration (minimum 30 minutes for a new patient)
- History, assessment and management proformas are often helpful to ensure that an adequate assessment is made, with efficient use of time. The description of the episodes should be clearly documented, ideally a first-hand or witnessed description of the beginning, middle and end of the event(s) if possible.
- Review of a video/videos of the episodes in question are increasingly easy for parents/carers to obtain, and are of great use alongside descriptions of the episodes
- Young people should have the opportunity to spend time alone with the doctor and or ESN, to ensure that a confidential young people's consultation takes place.

- There is no test that can diagnose epilepsy, however in certain circumstances, some tests can be useful in investigating suspected seizures, things that may have provoked the episodes, or to rule out alternative diagnoses. There should be access to relevant investigations within 4 weeks of request. These may include electrocardiogram (ECG), electroencephalogram (EEG) – awake (standard) or sleep, Magnetic Resonance Imaging (MRI) or other neuroimaging, blood and urine tests.
- Guidance on who needs MRI and other neuroimaging are clearly detailed by NICE and those recommendations should be followed. MRI may be needed awake (with or without play specialist support), sedated or under general anaesthetic. Where the appropriate option is not available, there should be clear pathways for referral, such that the investigation takes place within the defined timeframe.
- Guidance for who needs EEG are clearly documented in NICE guidelines, and generally an EEG is recommended after the second suspected epileptic seizure. If EEG is not available locally there should be clear pathways for referral to the most appropriate centre with equality of access to that service. Sleep EEGs, where needed, can be following sleep deprivation or with the use of melatonin.
- If the ESN is not available at the initial clinic assessment, then arrangements should be made for contact soon after.
- Safety advice should be given whilst waiting for investigations to be completed and may include water safety, care around heights, travel and other activities, and driving restrictions for older patients.
- For some CYP, antiepileptic medication will be recommended after the first consultation if it is clear from the history, or review of video, that they have a recognised seizure syndrome.
- For CYP who have had a convulsive seizure greater than 5 minutes in duration, or a cluster of three or more shorter seizures within an hour, then rescue medication (that can be given to stop a seizure) with buccal midazolam should be prescribed with one dose provided for home and for other regular carers and one for school. Training should be provided for when and how to give the medication in addition to basic life support training for the carers. A Care Plan should be provided for school following liaison between the ESN and school nurse (or relevant professional at school).
- If there is any diagnostic uncertainty, referral to a paediatric cardiologist should be considered.
- If there is any developmental regression (i.e. someone who has lost skills they had obtained previously), stasis or slowing of developmental progress - or an inability to identify a recognised seizure syndrome - there should be an urgent referral to tertiary care for advice and support.
- Details for a point of contact for the local CYP epilepsy team (secretary, ENS or Doctor) should be given to the parents/carers and, where appropriate, the young person - in case they need to get in touch before the next appointment.



## Subsequent appointments for those diagnosed with epilepsy

- The Paediatrician with Expertise in Epilepsy and / or the ESN should meet with the child, young person and their family as soon as possible after the relevant investigations are complete.
- The suspected diagnosis should be made using the latest ILAE (International League Against Epilepsy) multi-axial classification and where appropriate an epilepsy syndrome given. This should then be explained to the family and child/young person using language that is easy to understand. This will include an explanation of the expected course of the epilepsy syndrome and ongoing care from the team.
- Where warranted, anti-epileptic drugs (AEDs) should be commenced in line with NICE guidance or other up-to-date, evidence-based practice. Appropriate formulations should be considered in order to optimise adherence/concordance with the medication.
- Common side effects from the chosen AED should be explained and, in cases where there is a choice of treatment, the parents and young people should be involved. As per BNFC (British National Formulary for Children) guidance for certain drugs, it is important to stick with one formulation and, where possible, monotherapy (i.e. using one AED) should be recommended.
- Other information given should include:
  - safety advice including water, sleep and travel safety,
  - information about charities and third sector organisations,
  - written information about medication management and sudden unexpected death in epilepsy (SUDEP) where relevant.
  - NB: if there is no ESN available within the secondary care service, then the paediatrician would need allocated sufficient time to provide this care (e.g. a double appointment slot).
- Where appropriate, the child or young person may need to be referred onwards to tertiary care at this point and share care moving forwards. This would include if one or more of the following were present:
  - the epilepsy is not controlled with medication within 2 years
  - management is unsuccessful after two drugs (AEDs)
  - the child is aged under 2 years
  - a child or young person experiences, or is at risk of, unacceptable side effects from medication
  - there is a unilateral structural lesion
  - there is psychological and/or psychiatric co-morbidity
  - there is diagnostic doubt as to the nature of the seizures and/or seizure syndrome.
- Tertiary care specialists should see the child or young person within four weeks of referral.
- Children and young people with specific syndromes such as Sturge–Weber syndrome, the hemispheric syndromes, Rasmussen's encephalitis and hypothalamic hamartoma should be referred to a tertiary epilepsy service.

- In addition if there is developmental regression, stasis or slowing of developmental progress - or inability to identify a seizure syndrome - then a referral to tertiary care then a referral should be made and the child should be seen more urgently.
- The parents/carers and young people where applicable should leave the appointment with clear contact details in case of questions and ongoing care requirements.

## Subsequent clinic attendances

- These should be at least annually with the paediatrician with expertise in the Epilepsies and ESN for a structured review though most patients will receive more frequent appointments and ongoing care via the ESN or paediatrician. If there is no ESN allocated to the service then more frequent consultant led appointments will be required. The frequency of the reviews should be agreed between the specialist team and the family
- They should be of adequate length – minimum of 30 minutes shared between the consultant and ESN together or apart. For young people extra time is needed to be seen alone.
- The annual structured review, regardless of seizure frequency includes:
  - Frequency and type of seizures in the context of the defined seizure syndrome.
  - Current medication formulation and dose including adherence and tolerability.
  - Review of whether medication may be discontinued and plan for when that may be. This may also include review of the need for rescue medications if there have been no seizures in the past year.
  - Functional aspects of the impact of epilepsy and general wellbeing and quality of life
  - Growth and development
  - School performance
  - Sleep quality
  - Safety advice review
  - Access to benefits
  - Check that carers are confident with emergency care and that there is a current Care Plan in place at school.
  - For teenagers, time alone to discuss the diagnosis and adherence, home, school life and activities, careers, sleep, mood, sexuality and contraception, alcohol, substance use and anything else that they would like covered.
- If the child or young person continues to have seizures despite apparent good adherence to medication the diagnosis of epilepsy should be questioned.
- If non epileptic attacks are suspected then it should be remembered that epilepsy and non-epileptic attacks may co-exist.
- If there is diagnostic uncertainty referral to a paediatric cardiologist should be considered
- CYP with epilepsy should be signposted to available self-management and peer support opportunities wherever possible.

## Referral to tertiary care

Where appropriate, a child or young person may need to be referred onwards to tertiary care. This would include if one or more of the following:

- the epilepsy is not controlled with medication within 2 years
  - management is unsuccessful after two drugs
  - the child is aged under 2 years
  - a child or young person experiences, or is at risk of, unacceptable side effects from medication
  - there is a unilateral structural lesion
  - there is psychological and/or psychiatric co-morbidity
  - there is diagnostic doubt as to the nature of the seizures and/or seizure syndrome.
  - specific syndromes such as Sturge–Weber syndrome, the hemispheric syndromes, Rasmussen's encephalitis and hypothalamic hamartoma should be referred to a tertiary epilepsy service.
- Tertiary care specialists should see the child within four weeks of referral.
  - In addition, if there is developmental regression, stasis or slowing of developmental progress - or inability to identify a seizure syndrome - then a referral should be made and the child should be seen more urgently.

## 13-18 year olds and transition to adult services

Successful transition starts as early as possible and should be based on the Healthy London Partnership CYP acute care standards.

- Where possible, young people's clinics should be held separately, with time allocated to see the young people alone. There may be additional resources available as part of these clinics, such as access to youth workers, careers advice, sexual health services etc.
- Female patients should be prescribed folic acid 5mg daily if sexually active and consideration given to contraception taking into account the AED they are on.
- If on taking sodium valproate due to choice and no alternative then contraception pregnancy avoidance should be discussed at every visit and clearly documented.
- One example of a highly regarded transition pathway that is being adopted across many sites is the Southampton is "Ready Steady Go" program where three clear stages of transition are identified and where patients gradually gain more independence till transition to adult care.
- There should be a clearly identified pathway to transition to adult services at the right time. Evidence shows that the later this takes place the better the outcome.

- As a minimum, at the end of the transition pathway there should be a 'handover clinic' joint with an adult neurologist although a joint clinic with an adult neurologist for a couple of appointments beforehand is preferable.

### **Access to psychological services and other mental health support.**

There should be clear pathways of care with Mental Health services for CYP with epilepsy, either liaison or community. This includes support for:

- The assessment and management of CYP with a suspected psychiatric co-morbidity such as depression, anxiety or where significant self-harm has taken place or a risk of this is suspected
- Where neuropsychological assessment has been considered to evaluate learning concerns and cognitive dysfunction, particularly in regard to language and memory.
- Where neuropsychological assessment is indicated: when a CYP with epilepsy is having educational or occupational difficulties, when an MRI has identified abnormalities in cognitively important brain functions or when a CYP complains of memory or other cognitive deficits and/or decline. This may happen in tertiary care.
- Where psychological interventions (relaxation, cognitive behaviour therapy) may be needed.

## **2.4 Urgent and Emergency Care**

Children with new onset seizures or those with seizures that are poorly controlled or prolonged greater than 5 minutes may present to secondary care services, usually directly to the Emergency Department (ED)

### **Children and Young People presenting in Status Epilepticus**

- Generalised convulsive (tonic-clonic) status epilepticus is defined as a generalised convulsion lasting 30 minutes or longer, or repeated tonic-clonic convulsions occurring over a 30 minute period without recovery of consciousness between each convulsion. However, the guideline stated that 'for practical purposes, the approach to the child who presents with a tonic-clonic convulsion lasting more than 5 minutes should be the same as the child who is in "established" status – to stop the seizure and to prevent the development of status epilepticus'.
- Hospitals should have clear resuscitation guidance available for their teams, with easy access to the required treatments, and access to appropriate anaesthetic support if intubation and ventilation is required.
- There should be clear pathways of care to intensive care if needed, either on-site or via a dedicated children's emergency transport team.

Causes of status epilepticus could include:

- Febrile convulsion

- Known epilepsy +/- acute illness
- Infection such as meningo-encephalitis
- Metabolic / electrolyte disturbance
- Trauma (including non-accidental injury)

When assessing it is important to consider

- The duration of seizure
- Nature of seizure -generalised or focal.
- Treatment given so far -the patient should not have more than two doses of benzodiazepines, or respiratory depression could occur.

## Treating convulsive status epilepticus

The expected emergency treatment, as per APLS (Advanced Paediatric Life Support) guidelines, is detailed in the Appendix.

## Non-convulsive status epilepticus in children:

This is less common than tonic-clonic status epilepticus. Treatment for non-convulsive status epilepticus is less urgent than for convulsive status epilepticus. Treatment should be led by a senior paediatrician who may need to liaise with a paediatric neurologist. Reinstatement of their medication or a trial of benzodiazepine may be considered.

## Children and young people presenting following a suspected seizure

Children and young people commonly present to the ED following an episode (paroxysmal event) that may be epileptic or non-epileptic in nature.

### *Structured assessment*

- Many children presenting with paroxysmal episodes do NOT have epilepsy
- The paediatric assessment should include a thorough history, from eye witnesses and symptoms from the child, as well as prospective recordings (video / written) where possible. The developmental and family history should be recorded.
- A physical examination, including neurological and skin examination as well as brief developmental assessment should be performed.
- Children who have presented with focal onset seizures, have residual limb weakness or who have worrying seizures such a history of a prolonged seizure greater than 5 minutes or infantile spasms should be discussed with a senior paediatrician and or the Consultant with Expertise in Epilepsy in order to agree next steps
- An easy to use proforma for history, examination and subsequent plan may be available to guide a time efficient history, assessment and next steps.
- Anyone with a decreased level of consciousness should be managed appropriately, as per a local guideline or, if not present, the RCPCH “Management of children and young people with an acute decrease in conscious level” guideline (2015).

### *Initial investigations to consider*

- If the professional assessing the child or young person is not sure about the nature of the episode, it is better to discuss with a senior paediatrician in order to avoid unnecessary investigations and anxiety. Sometimes the history alone or a video recording can identify a typical non-epileptic paroxysmal event such as breath holding or self-gratification in a toddler
- Blood tests including glucose, electrolytes, calcium and magnesium should be undertaken following convulsive seizures.
- A 12-lead ECG should be performed in adults with suspected epilepsy and the majority of children and young people with convulsive seizures. This is to exclude QT abnormalities or arrhythmias. The QTc should be corrected manually and should be less than 0.45seconds (and greater than 0.35seconds). Consideration should be given to referral to a paediatric cardiologist if there are any concerns regarding cardiac pathology.

### *Subsequent tests:*

These are usually at the discretion of the paediatrician with expertise in epilepsy, but a senior paediatrician may request EEG or neuroimaging according to NICE criteria.

### *Subsequent management:*

Admission to hospital will depend on the severity and frequency of seizures. If discharged from hospital, then appropriate safety advice will need to be given especially relating to water safety, heights and travel.

For CYP with a known diagnosis of epilepsy, details of the attendance to ED (or admission as an inpatient) should be communicated to the named epilepsy team. It may be that scheduled review should be expedited, that further investigations need to be carried out, or that adjustments in therapy can be actioned.

If a convulsive seizure has lasted greater than 5 minutes in duration or there have been more than three shorter seizures in an hour then consideration should be given as to whether buccal midazolam should be prescribed as rescue therapy. This may also be considered after a focal seizure lasting greater than 15 minutes in duration. Appropriate training and support will need to be provided to the parent and carers and an Emergency Care Plan provided.

## 2.5 Tertiary Care

### Background

The diagnosis and management of epilepsy in children may not be straightforward for a number of reasons, any of which may prompt referral for a tertiary opinion. In particular, initially there can be diagnostic issues which may be challenging and, even with best practice, there may need to be revision of the diagnosis over time. Numerous studies have previously highlighted misdiagnosis rates and a number of educational initiatives have been introduced to support professionals in this field, both locally and nationally, alongside wider availability of appropriate diagnostic services.

Following diagnosis of a type of epilepsy, the next steps are then usually:

- to better define the epilepsy syndrome where this is possible
- to explore the underlying cause whether genetic, metabolic, structural, inflammatory/immune mediated or unknown
- to identify co-morbidities (which may include cognitive and/or social communication difficulties, motor co-ordination difficulties, behavioural or psychiatric disorders).

A number of challenging to treat epilepsies, associated with high seizure burden and relative treatment resistance, present in infancy and young children. CYP with any of these are vulnerable to severe developmental and behavioural consequences and major impact on family functioning, so that this is a specifically high risk group.

### Referral

Tertiary referrals would usually come via the secondary care team, though sometimes the initial presentation is via another specialist team, or the epilepsy has been judged to need tertiary input from the outset.

However, it is crucial that the care of CYP with epilepsy is shared with secondary care services, such that expert wider paediatric input can be given where needed and close links to nursery, school or college, local therapy and child and adolescent mental health services (CAMHS) can be maintained. The GP is also a vital link in understanding the wider family context and should be included in all communication.

### When is tertiary referral indicated?

#### *Immediate or early referral*

- if there is developmental regression, stasis or slowing of developmental progress
- in a young child (age under 2) – even with an identifiable underlying diagnosis, young children benefit from an early holistic review of their epilepsy and potentially related difficulties

#### *Other indications for referral*

- there is ongoing diagnostic doubt as to the nature of the seizures, or some of the episodes.

- there is ongoing discussion or uncertainty as to the underlying epilepsy syndrome, which may include discussion as to the relevance of genetic testing.
- there is an identified unilateral structural lesion (including hemispheric or multi-lobar pathology)
- the epilepsy occurs in the context of specific syndromes (e.g. Sturge Weber, hypothalamic hamartoma or with tuberous sclerosis (TS))
- the epilepsy occurs in the context of Rasmussen's encephalitis or with presumed neuroinflammatory disorders
- there is an underlying metabolic disorder (such as a glucose transporter disorder), or questions as to a possible underlying metabolic disorder
- two appropriate AEDs have been tried and, despite this, there are ongoing seizures (even if the frequency is reduced, or there are reported intolerable side effects of treatment)
- seizures continue after 2 years of treatment
- assessment and potential intervention with regard to associated co-morbidities would be helpful or potentially helpful

Following referral, there is a recommendation that children be seen by tertiary services within 4 weeks.

For urgent referrals, it is good practice to hold an initial telephone conversation with the tertiary neurology service on-call (e.g. in the case of an infant presenting with very frequent seizures, those needing intensive care support, or in developmental regression, stasis or slowing of developmental progress). In the situation where there are longstanding diagnostic or management difficulties, such discussion may also facilitate further investigation (e.g. prolonged EEG monitoring (telemetry)), so that this is undertaken in parallel with the specialist review.

## **Delivery and organisation of tertiary services for CYP with epilepsy in London**

Tertiary care paediatric epilepsy services are usually centrally located in a teaching hospital, which may be a dedicated Children's Hospital or large children's department in a major hospital. This implies co-location with other specialist services for children, but there would be expected to be well-defined pathways for communication with linked paediatric units within the region both in the acute and community paediatric setting.

Specifically there should be shared care pathways with Lead paediatricians with expertise in the epilepsies and local Epilepsy Specialist Nurses (ESNs) in each locality served. As such, services should be delivered as part of a clinical network with opportunities for joint working with tertiary and secondary care and with appropriate peer review, audit and education within that network.

Tertiary services for CYP with epilepsy based in London also have a remit to deliver services across their wider network, which means families travelling long distances to the centre, emphasising the value of tertiary outreach clinics where organisation and workforce planning allows. For children in London, the tertiary unit may well be their local as well as tertiary unit, and it is important to ensure that within the same hospital there are also clear pathways for referral (i.e. from secondary to tertiary care).

Tertiary services may be delivered:

1. through inpatient service
2. through outpatients at tertiary centre
3. face to face in joint paediatric neurology/epilepsy clinic with local paediatrician with expertise in epilepsy and local ESN
4. via Skype/video call, telephone or email contact with families and local teams.

Specific, up-to-date information on available tertiary services in London can be found on the NTPEN (North Thames Paediatric Epilepsy Network) and SETPEG (South East Thames Paediatric Epilepsy Group) websites:

- <https://www.gosh.nhs.uk/medical-information/clinical-specialties/north-thames-paediatric-epilepsy-network-information-health-professionals>
- <http://www.setpeg.co.uk/>

## Workforce

Onward referral to tertiary care, within the epilepsy pathway, is likely to be to a *Paediatric Neurologist* in the first instance. This is a children's specialist - a consultant who has undertaken paediatric training but then, in addition, extensive training in the assessment and management of neurological disorders in children, of which epilepsy is one of the major conditions seen. In this role, they are likely to:

- see acutely neurologically unwell children, on occasions in conjunction with colleagues in intensive care
- see children with long-term conditions or for assessment in outpatients
- deliver teaching
- participate in clinical trials for children and other research roles
- maintain their practice through regular education and peer review.

Paediatric neurologists may either work:

- as part of a small group of paediatric neurologists based in one NHS Trust (typically 3-4) and maintain a knowledge of all the major neurological conditions, including epilepsy, with or without further subspecialisation, or
- as part of a larger group (if based in a large children's hospital), so there may be one or more paediatric neurologists in that team who has a major epilepsy component to their role.

However, paediatric neurology services are much wider than just the paediatric neurologist(s). Tertiary services have other staff including:

- linked Nurse Specialists (including ESNs, some with specific sub-areas of expertise)
- specialist therapy services (including Physiotherapy, Speech and Language Therapy, Occupational Therapy)
- mental health professionals (such as Clinical Neuropsychology, and with close links to child Psychiatry including Neuropsychiatry)
- close links to other professionals such as: sleep medicine, and other non-neurological specialities (e.g. genetics, metabolic medicine, cardiology, respiratory medicine, gastroenterology, orthopaedics and palliative care).

## Investigations

There is also a need for supporting investigations and facilities for those investigations, including:

- EEG: ranging from short recordings to prolonged (several days and nights). In some centres longer EEG monitoring may now be undertaken in the home rather than in hospital, with benefits for event capture and for ease for family but, if preferred, hospital-based monitoring with child and parent or carer alongside is available.
- Imaging: this may include structural imaging with MRI or CT (the latter more often acutely), or functional imaging with fMRI, PET or SPECT. On occasions these studies require very careful planning and organisation and functional studies are much less widely available.

## Specific pathways within tertiary services

Certain other specialist pathways often form part of tertiary services:

### *1 Services for children with potentially surgically remediable epilepsies – CESS*

The NHS England Advisory Group for National Specialised Services (AGNSS) launched CESS (Children's Epilepsy Surgery Service) in England as an NHS initiative to improve access to epilepsy surgery for children and earlier referral and to increase rates of surgery. Four centres were nationally designated for CESS with the goal of also improving the quality of the services offered to patients by concentrating expertise.

In London, Great Ormond Street Hospital works with Kings College Hospital to deliver the largest epilepsy service for children in the UK. This service sees children and young people from infancy, up to and including 18 years. Referrals usually come from paediatricians with an expertise in epilepsy in secondary care, or from paediatric neurologists within or outside the CESS centre.

Teams from the four CESS centres meet regularly to discuss cases, share expertise and to provide education and training to colleagues both internal and external to the network. As a nationally commissioned service, data on service delivery as well as outcomes is collected on a continuous basis.

### *2 Access to non-drug therapies*

Dietary therapies and neurostimulation (specifically vagal nerve stimulation (VNS)) should now be regarded as being standard options in management of CYP with epilepsy who have not responded to appropriate initial AED therapy. However, these will not be appropriate for all, either from the child or young person's perspective, the family standpoint, or in the clinician's judgment.

It is important that CYP and their families have access to appropriate and informative materials to consider these modes of treatment, and that those delivering these treatments are experienced and able to offer training and monitoring regarding dietary therapies, and post implantation management of VNS. Children being considered for VNS should be discussed in an

epilepsy surgery pathway to ensure that they are not a candidate for resective surgery, as this may offer better rates of seizure freedom in selected cases.

### 3 Ketogenic diet

Regarding the ketogenic diet (KD), the following should be followed:

- Many medicines contain some form of carbohydrate so, for any new medications that are started, it is important that the most suitable formulation and brand for the KD is selected
- Current medicines must be assessed and the most suitable formulation and brand selected.
- Once established on the KD, it is important that any new medicines that are needed are appropriately selected.
- Parents or carers must tell hospital doctors/nurses/GP/community pharmacist that their child is on the KD, and so requires medicines that are carbohydrate free/low carbohydrate.
- Tablets are generally better than liquids – so if in doubt use tablets.
- Suppositories are ok, even if they contain carbohydrate, as it is not absorbed.
- Ketogenic diet stickers – should be used on drug charts if a child is admitted to hospital.
- Intravenous fluids containing glucose should be avoided, unless a child has low blood glucose levels.
- If a new medicine is started, then ketones should be monitored - and the KD team if there are concerns that the medicine is causing a reduction in ketones.
- The following should be avoided: sucrose, fructose, dextrose, sorbitol, glucose, mannitol, glycerol, starch, maize starch, lactose, maltodextrin.
- Pain relief:
  - Paracetamol - the Medinol brand of paracetamol is the most 'keto-friendly'. It may be worthwhile to keep a bottle at home as not all pharmacies may not stock this particular brand.
  - Ibuprofen – the Fenpaed brand of ibuprofen is keto-friendly.
- Antibiotics:
  - Tablet and capsule antibiotics are not usually suitable to use for children on the KD, as the strengths are not appropriate for young children; they also contain higher levels of carbohydrate.
  - There are lots of different brands of liquid antibiotics available; make sure a sugar-free liquid is prescribed. They may contain sorbitol so ketones should be monitored.
- Laxatives for constipation:
  - The common laxatives used in children (lactulose and senna) contain big amounts of sugar so should be avoided. Movicol can be safely used in the KD; if lactulose is needed, then the Novartis brand can be safely used. Suppositories and phosphate enema are suitable to use, but will need to be prescribed by a doctor.

### 4 Specialist clinics for rare conditions

Many tertiary centres hold specialist clinics for rare disorders, for example:

- children with neurocutaneous disorders where epilepsy is one part, such as Sturge Weber syndrome, TS or neurofibromatosis
- neurometabolic clinics where the epilepsy may contribute to management difficulties but there may be highly specific treatments based on the underlying disorder (e.g. in glucose transporter disorders where the ketogenic diet is a specific treatment, even if used much more widely in other forms of epilepsy)
- children with rare progressive disorders such as the NCLs (neuronal ceroid lipofuscinoses)

### *5 Joint epilepsy genetic services*

With the rapid expansion in genetic diagnoses in epilepsy, such services are likely to develop further.

## 2.6 Childhood epilepsy: particular considerations at different ages

This section outlines some of the particular considerations when diagnosing and managing epilepsy in children, based on age groups.

### Under 2 years

Young children in this age group who have been diagnosed with an epilepsy should always be referred on to tertiary neurology. This is a crucial time in a child's development, and so even those who have an otherwise identifiable diagnosis would benefit from:

- thorough investigation (specific further investigation if developmental regression is present (loss of skills that had previously been obtained), stasis or slowing of developmental progress)
- an early holistic review of their epilepsy
- identification/management of the functional impact
- referral on to relevant services to optimise developmental progress

### School age

For the majority of school age children as they get older, many of the aspect of management are related to working around their day-to-day lives, as they become increasingly independent of the home environment. The overarching aim is to ensure children and young people stay healthy and start to develop safety awareness, whilst achieving optimal participation in normal activities for someone of their age and stage of development.

Common examples of issues encountered by CYP of school-age include:

- not being able to attend sleepovers or even visit a friend's house without their parents,
- not being able to walk to school with friends and/or requiring a lift to school or college due to a risk of seizures
- being prevented from doing PE classes, going on school trips or outings due to a lack of trained staff.

The stigmatising nature of discriminating in this way against CYP, and the harm it can do to their development, confidence and sense of self, mean that it is the responsibility of all professionals involved in providing care, to advocate for children and young people to achieve this.

### Adolescents

Older teenagers, with developing autonomy and independence, need proper support to ensure they engage with managing their epilepsy and its impact. In taking this approach, young people can feel empowered to make decisions about their epilepsy, and include this in their thinking about their futures as they prepare to take control of their own health, lifestyle choices, career/academic paths, independent/supported living.

Common examples of issues encountered by adolescents with epilepsy include:

- Pregnancy, contraception and discussions around sex and sexuality. These may require signposting to those with specialist knowledge, particularly around managing of AEDs.

- Risk management around usual adolescent lifestyle issues and events, such as socialising with peers independently, using alcohol responsibly, etc.
- Coping with stress around exams
- Issues with sleep (usually lack of sleep or poor sleep hygiene)

It is important that individual adolescents feel able to discuss these issues openly and honestly with professionals involved in their care, so that support and signposting can be offered.

## 2.7 Mental health and behavioural problems

Young people with epilepsy are at significantly increased risk of developing mental health and behavioural problems. This likely to be for a number of reasons, including:

- coincidental mental health and behavioural problems form the condition itself (i.e. independent from seizure frequency and AEDs).
- the direct effect of the seizure
- the effect of the treatment of the epilepsy/medication
- social pressures, stigma and isolation
- chronic illness

### Co-incident mental health problems

Young people with epilepsy are a risk of developing co-incident mental health problems unrelated to the seizure disorder. This is a large unmet need that is becoming increasingly identified, with 46% of children in one study meeting diagnostic criteria for a behavioural disorder.

### The seizure

Some young people might have a change in their behaviour before, during or after the seizure. For hours or even days before the seizure, in the prodromal phase, alterations in mood might be seen.

During a focal seizure the young person might display a change in behaviour which they are unaware of including laughing, crying, lip smacking or running around. This is part of the seizure.

After a seizure the young person may sleep or be drowsy. They can be confused and their vision and speech may be disturbed.

A rare and infrequent complication is post ictal-psychosis. This presents with delusions or hallucinations and requires expert assessment and management

In the longer term, if the epilepsy is not well controlled the seizures can have a direct effect on the brain with the risk of hypoxic brain damage

### Medication

Medication prescribed to reduce the frequency of seizures can also cause a range of behavioural problems. These include effects on learning, memory difficulties, over activity and poor concentration, aggression, sleepiness and fluctuating mood

### **Social pressures**

Society has a role to play in how people with epilepsy are perceived. There is a stigma attached to having seizures which inevitably impacts on the young person and how they are accepted by their peers and also by their family and teachers. This, in turn, impacts on the emotional wellbeing of the individual and their resilience regarding the development of behavioural or mental health problems. The risk of bullying is increased with associated fear and anxiety. Friendships can be problematic and peer support might not be accessible.

### **Effects of chronic illness**

Having a chronic illness results in frequent short term and, sometimes, long term absences from school. This affects learning and behaviour. Parents and teachers may be over protective.

### **Assessment and management**

Concerns about behavioural or mental health problems should be raised with the young person's GP, paediatrician or neurologist. They will be able to decide if an assessment from a mental health team is indicated, followed by specialist intervention

## 3 Care planning

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### 3.1 The 'Care Plan'

All children and young people with epilepsy should have an Individualised Health Plan (IHP) that is agreed between the young person, family and/or carers, school and primary, secondary and (if relevant) tertiary care. It is important that the school both contributes and takes guidance from this care plan so that the CYP have access the same activities as their peers.

The Care Plan should include lifestyle issues, as well as medical issues. This should include what to do in the event of a seizure (especially prolonged seizures), as well as tailored advice for that individual young person. It should be reviewed annually, or sooner if changes are warranted.

CYP with a history of prolonged or repeated seizures should have an agreed written emergency care plan as part of the IHP. Children with recurrent status epilepticus should have an individual treatment pathway, formulated and agreed at local centres, and detailed within the IHP. The emergency care plan and specific treatments should be written clearly in clinic reports (i.e. the record of the medical care plan).

Permission should be sought to share documentation with the child/young person's school/college and other relevant professionals (e.g. social worker, mental health professional) to encourage joined up care.

It is good practice for the young person and family to have written evidence of their care plan in case of emergency, so they should always receive a copy of their IHP, be advised to have it available in case of a seizure. Examples of a common tool used for this purpose are: the RCPCH Epilepsy Passport, clinic letters, IHP templates provided by local epilepsy or community nursing teams, or a combination of these.

### 3.2 Individual Healthcare Plans (IHP)

If a child has a medical condition, a school has to put things in place to support them (whether or not the child has special educational needs). This is written in the Children and Families Act (2014), and there is guidance to support this requirement, explaining what the local authority and school should do. Under the Act, the school should provide the same opportunities for the child as any other child in the school.

All schools and colleges should have the following in place for children with epilepsy:

- a plan to ensure all staff and children have an understanding of epilepsy
- if needed, a child's epilepsy medicine in school and staff trained in how to give it
- a clear understanding of what an emergency situation would be and how to respond to it
- [Individual healthcare plans](#), including who will be responsible for what and when. This information should be collected by talking to the child, parents and healthcare professionals, and it should be reviewed on a regular basis

<https://www.epilepsy.org.uk/info/education/individual-healthcare-plans-ihps>

<http://www.youngpilepsy.org.uk/dmdocuments/IHP-child-form.pdf>

## Emergency care plans

All children with epilepsy should have an emergency and/or symptom management plan for their care if having seizures. This should be available for home, school and any other external activities/organisations they attend.

Emergency care plans should contain certain information as standard, including:

- up-to-date demographic details for the child/young person, including next of kin contact details
- a detailed seizure description of the child/young person's seizures from their parent/carer, after discussion with a specialist nurse or paediatrician.
- a classification of the child/young person's seizure
- a description of the child's normal post-ictal phase (i.e. making it clear this is not an active part of the seizure)
- immediate care and instruction for managing a seizure, including cluster management as required.
- emergency medication (if applicable), with care instructions, plus when and how to administer
- when to summon paramedic/ambulance support
- when to contact parents
- sports and leisure advice, including around:
  - swimming and water safety
  - trips out with school
  - climbing advice
  - NB: a factsheet on sports and leisure information can be sent to schools and colleges, with any specific needs outlined in the care plan.
- Details of any ambulance directives in place for children under their care.

An example of a readily available Emergency Care Plan tool is the RCPCH (Royal College of Paediatric and Child Health) *Epilepsy Passport*, which contains essential up-to-date information about a child or young person's epilepsy, including their emergency care plan, medication history and key professional contacts. It can be downloaded here:

[www.epilepsypassport.org.uk](http://www.epilepsypassport.org.uk)

## Organisational training

Schools and other organisations should have suitable training to manage safely a child within the organisation. If this is identified to not be the case, the school nurse or ESN can be approached to provide appropriate training to allow safe inclusion of the child (e.g. includes sports and leisure advice, water safety, trigger avoidance, organisation external trip management and safe staffing to support inclusion of a child in all activities possible safely). Such training should be yearly for all schools.

## Emergency seizure medication at home, schools and other organisations

The following standards around emergency seizure medication should be followed:

- a CYP's emergency medication should be reviewed at least yearly and care plan adapted at that time to reflect any change in care.
- schools, colleges and other relevant organisations should have training for key staff and individuals on administration of emergency medication and seizure first aid, ensuring there are always 2 members of staff who can administer medication (allowing for leaves of absence through sickness and annual leave).
- schools and colleges should be given information on emergency medication, and how to appropriately store them at school.
- school/college staff and parents to be aware of expiry dates of medications and to ensure there is always an appropriate supply at school, including returning them to school after holidays.
- for schools to revert to calling 999 in the case of medications not being available and to not exclude children from school in the case of absent medications unless the child requires emergency medications more often than once a week.

### **Adherence to care plans.**

For schools, organisations and families to have adherence to care plans measured to ensure a child is being cared for in accordance with their agreed and consented care plan that is in place. Where this does not occur an urgent review will take place to find out why this is not happening and to look at reasons and amend practice or care plans as necessary.

### **Pupils, friends and peers inclusion and learning about epilepsy.**

For schools and epilepsy services to work together to assess and deliver appropriate and targeted learning for a young person diagnosed with a seizure disorder or epilepsy their friends and peers according to the wishes and consent of the organisation, school, young person and family.

### **Communication between health and educational services**

Improving communication between health teams and education ensuring relevant information is shared in both directions. A good example is the copying of clinic letters copied to school nursing teams or allocated nurses. When educational update requests are made to schools by the epilepsy service asking for an educational assessment of the child, or requesting an update on their educational standard this should be answered in writing (usually either a letter or email).

## 4 Schools, colleges and educational organisations

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Since 2014, all state schools in England have been legally required to have a policy on supporting children with medical conditions. This means that:

- all CYP with epilepsy should have an individual healthcare plan (IHP)
- school staff should be trained to meet the needs of CYP with epilepsy
- schools also need to take into account how a young person's condition might affect their learning.

By having these in place, schools (and other educational organisations) should be in a position to ensure that CYP with epilepsy have the support they need to be safe, included and achieve their potential.

Unfortunately, a survey carried out by Young Epilepsy in 2017 showed that many young people with epilepsy were receiving inadequate support, with:

- only 45% being at a school with a medical conditions policy
- 36% not having an individual healthcare plan (IHP) at school
- even for those that did have an IHP, it did not always contain information on what to do in an emergency (11%), when a seizure occurs (8%) or details of current medication (16%)
- impact on learning not forming part of IHPs (67%)
- 18% being excluded from activities at school

<http://www.youngepilepsy.org.uk/for-supporters/epilepsy-at-school-campaign/>

### 4.1 London epilepsy guide for schools

To help improve these outcomes, the Healthy London Partnership published a special London epilepsy guide for schools in 2016:

<https://www.healthy london.org/hlp-archive/latest/publications/london-epilepsy-guide-schools.html>

This document stated that:

- Every child with epilepsy should have an individual healthcare plan. This should include what to do in the event of a seizure (and especially prolonged seizures), as well as other tailored advice for that individual young person.
- Children and young people should be supported throughout their education, recognising the impact that epilepsy has on learning, behaviour, mental health and wellbeing.
- Prompt identification of learning and behaviour needs in children with epilepsy is vital.
- Each school should have an up-to-date medical conditions policy.
- Children and young people with epilepsy should have appropriate supervision depending on their individual needs.
- Children under five need consideration of 1:1 support at school (in the absence of a parent). This may need an education health care plan to support and may need funding. Primary school aged children and young people (6 years+) require support to manage their epilepsy in school in line with the Children and Families Act 2014. In secondary school, students will be largely independent but may require intermittent support.

## 4.2 Special Educational Needs or Disabilities (SEND)

In 2014, the Children and Families Act also established a new framework of support for children with special educational needs or disabilities (SEND) in England. Under this framework, school, colleges and educational establishments have the following roles:

### *Identifying learning concerns*

- Schools and colleges should be vigilant to the increased likelihood of cognitive difficulties in CYP with epilepsy. The ABLE screening tool, created by Young Epilepsy, may be helpful in this: [http://www.youngepilepsy.org.uk/dmdocuments/Assessment-of-Behaviour-and-Learning-in-Epilepsy-ABLE\\_2015.pdf](http://www.youngepilepsy.org.uk/dmdocuments/Assessment-of-Behaviour-and-Learning-in-Epilepsy-ABLE_2015.pdf)

### *Assessing and supporting learning for children with epilepsy*

- Educational assessments for those with identified learning concerns should be made by allocated professionals (e.g. educational psychologists, or paediatric health services) and then actioned by the educational organisation.
- Results and outcomes from the assessment should be shared with the CYP, their family, and other professionals involved in their care.

### *Inclusion not exclusion*

- Schools and educational organisations must understand the rights of the child and family around equity of inclusion and participation, in line with the Equality Act 2010, Children and Families Act 2014

### *Educational Health Care Plans (EHC)*

- CYP with epilepsy should to be assessed as an individual with educational needs without stigma, and the diagnosis of epilepsy should not be a barrier for inadequate assessment.
- Application for an EHC is better done early rather than late, in order to optimise the CYP's educational opportunities, and so improve outcomes.
- Those CYP being assessed for an EHC should have all services included in the assessment process, and in ongoing reviews of their needs.

### *Educational resources for schools, colleges and universities*

- All educational organisations have a duty to the wellbeing of their pupils and students. However, the independence of students as they get older should be reflected, such that young people and adult learners, in higher and further education, are encouraged to manage their epilepsy, though with appropriate support still offered.

However, this presents a challenging situation for a person with epilepsy due the unpredictable nature of seizures and their loss of consciousness causing effects and in fact this can make student in higher education more vulnerable and therefore resources for themselves, fellow students and staff are equally important to children at school. There are a range of resources available from the leading epilepsy charities as seen below.

All educational organisations have a duty to the wellbeing of their pupils and students however the independence of students as they get older is reflected in higher and further education and young adult and adult learners are expected to be more independent and therefore the older the student the less support to manage their medical condition is expected, this is a challenging situation for a person with epilepsy due the unpredictable nature of seizures and their loss of consciousness causing effects and in fact this can make student in higher education more vulnerable and therefore resources for themselves, fellow students and staff are equally important to children at school. There are a range of resources available from the leading epilepsy charities as seen below.

There are also resources here for school working with children with epilepsy in regards to learning needs the assessed difficulties of any child need to be managed by the educational psychologist and school as with any child regardless of their medical condition.

- <http://www.youngepilepsy.org.uk/for-professionals/education-professionals/resources-for-schools/>
- <http://learn.epilepsy.org.uk/training-for-schools/>
- <https://www.epilepsysociety.org.uk/school-education-and-epilepsy#.WlzE5fmLTIU>
- <https://www.epilepsysociety.org.uk/teaching-children-epilepsy#.WlzFTPmLTIU>
- <https://www.epilepsysociety.org.uk/university#.WlzFnPmLTIU>

### 4.3 Workplace

It is beyond the scope of this document to give guidance to employers. There are several guidance documents for young people wanting advice around employment and but information for aspects such as work experience and for giving young adults looking for work so they know their rights are below.

<https://www.epilepsy.org.uk/sites/epilepsy/files/B135-Work-and-epilepsy.pdf>

<https://www.tuc.org.uk/sites/default/files/EpilepsyInTheWorkplace.pdf>

## 5 Social care

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This section describes the context in which additional services for children may be provided by local authority children's services departments. These services are different from those provided by the NHS and are commonly referred to as 'social care services'. They cover a variety of arrangements and provision aimed at helping children in need and their families so that they are able to live an ordinary life.

### 5.1 Roles and responsibilities

#### What are the roles and responsibilities of different local authority professionals that provide care for CYP with epilepsy?

- Local Authorities have duties to provide services for children who are disabled. Whilst not all children with epilepsy would want to describe themselves as disabled, children with epilepsy *are* covered by the Equality Act, even if their seizures are controlled, or they do not consider themselves to be 'disabled'.
- Children and young people with epilepsy, even though they may not want to consider themselves as having a disability because of their condition, could be considered as "children in need", a concept set out in the Children Act 1989.
- There are some children with epilepsy who are so affected by their condition that they may have additional learning or physical disabilities that require additional support and services.

### 5.2 Social services and epilepsy

#### What is the structure of social care services that relate to epilepsy?

The context in which social care services are provided is in part under [The Children Act 2004](#), which requires every upper tier local authority to appoint a Director of Children's Services (DCS) and designate a Lead Member for Children's Services (LMCS).

The DCS and LMCS are appointed for the purposes of discharging the education and children's social services functions of the local authority. The functions for which they are responsible includes (but is not limited to): responsibility for children and young people receiving education or children's social care services in their area and all children looked after by the local authority. They should ensure that the safety and the educational, social and emotional needs of children and young people are central to the local vision.

It is for individual local authorities to determine their own organisational structures in the light of their local circumstances. This means that different local authorities can vary in their approaches. However, the DCS has professional responsibility for children's services, which means they are responsible for securing the provision of services which address the needs of all children and young people, including the most disadvantaged and vulnerable, and their families and carers.

In discharging these responsibilities, the DCS should work closely with other local partners, including NHS partners, to improve the outcomes and well-being of children and young people.

Local Authorities will put in place suitable arrangements to meet the needs of children as set out in various Acts and that are relevant to children's services. This will include assessing "children in need", "looked after children" and arrangements for child protection and safeguarding. The local authority has a duty to assess the needs of disabled children and has a duty to provide services to meet the child's assessed needs.

## 5.3 Legislation

### How does the legislation relate to children with epilepsy?

The law and procedures related to the provision of social care services for disabled children and their families is complex.

The main legislation that applies to disabled children, and a child with a chronic condition like epilepsy includes:

- Children Act 1989, which places a duty on local authorities to safeguard and promote the welfare of children within their area who are 'in need'.
- The Chronically Sick and Disabled Persons Act (CSDPA) 1970
- The Children and Families Act (CFA) 2014, which creates a new system to address the educational needs and related health and care needs of disabled children and young people aged 0–25.
- The Care Act 2014 which, although primarily an Act concerning disabled adults and their carers, also contains important provisions on transition to adulthood.

The *Children Act 1989* establishes the duty of assessment, which is generally crucial to the access of services and support. It requires the provision of certain specific services, particularly residential and foster care short breaks (which can be available to children with a disability.)

Local authorities are empowered to provide 'a range and level of services' to meet the requirements of 'children in need'. This should include providing family support.

A child is deemed to be a 'child in need' if:

- a) he/she is unlikely to achieve or maintain, or to have the opportunity of achieving or maintaining, a reasonable standard of health or development without the provision for him of services by a local authority ...; or
- b) his/her health or development is likely to be significantly impaired, or further impaired, without the provision for him/her of such services; or
- c) He/she is disabled.

Families should be able to seek an assessment for support for their child with epilepsy from Children's Services at least as a "Child in Need". If their epilepsy affects them in ways which means they have learning or physical disabilities they may also require other kinds of services including in some cases "being looked after" and offered residential, foster or respite care.

Families supporting a child with epilepsy may require additional support to manage the "social" aspects of the child's condition. The child may also need additional support to access education. These areas are what children's services would assess if a child were referred as "in need".

There is a low threshold for social care assessments, which should be carried out if a referral is made to children's services by a professional or family which indicates that child may be 'in need'. Whilst the assessment may be subject to a low threshold however, this can mean one of the possible outcomes may be a decision that the child is not in fact 'in need'.

The *Children and Families Act 2014* requires that local authorities have a view to ensuring that there is integration of educational provision and training provision, with health care provision and social care provision.

Authorities must also make joint commissioning arrangements with 'partner commissioning bodies' regarding the education, health and care provision to be secured for children and young people with special educational needs and disabled children and young people.

Key points of relevance in the Children and Families Act 2014:

- The replacement of 'statements of special educational needs' by *Education, Health and Care (EHC) plans*.
- The duty on local authorities to have in place a '*local offer*', setting out the provision (including care provision) which is expected to be available both within and outside the local authority's area.
- The duty on local authorities to keep under review social care provision both inside and outside their area.
- The duties in relation to integration and joint commissioning with the NHS.
- The duty to provide children, young people and parents with 'advice and information about matters relating to the disabilities of the children or young people concerned.

## 5.4 Expectations

What should children and young people and their families expect when they see different professionals and their teams? And what should professionals expect when they refer or signpost to other services?

As stated earlier in this chapter, children and young people with epilepsy are covered by the Equality Act (even if they do not wish to describe themselves as disabled), and so families should be able to seek an assessment for support for their children with epilepsy from Children's Services as a "Child in Need".

The 2015 guidance *Working Together to Safeguard Children* (*'Working Together'*) states that the purpose of assessment should 'always' be to gather important information about a child and family, analyse their needs, decide whether the child is a child in need and provide support to address those needs to improve the child's outcomes.

The guidance includes the requirement that:

- Assessments should be needs-led, rather than dictated by available provision.
- In consultation with all the children and adults concerned, the assessment process should identify:
  - the barriers that inhibit the child and family living an ordinary life, and
  - what can be done by the support agencies to tackle them.
- The child/young person's views should be taken into account.
- Assessment should take account of the needs of the whole family and individuals within it; while some services may be provided directly to a disabled child, others may be offered to parents or siblings
- The agreed provision or arrangements following assessment may not necessarily take the form of what are usually seen as social care services.
- There has also been a growing emphasis on assessment practice that adopts an 'outcome focus'. This means that the practitioner undertaking the assessment, together with the children and adults in the family, identifies a range of outcomes that are important to help the family live a more ordinary life. All involved then agree on the provision that could make those outcomes happen. The effectiveness of any intervention is then judged on the extent to which the identified outcomes are achieved.
- Assessments are undertaken by a social worker and should be timely.
- Assessments should be undertaken and provision put in place promptly and children and their families should not have to wait for essential services.
- Early intervention is regarded as important in order to avoid families reaching crisis point.
- Finally, because children grow and develop and family circumstances change, assessment of need should not be seen as a one-off event but should be repeated as required, while avoiding the burden that unnecessary repetitious assessments impose on families.

Local Authorities must have clear, published criteria explaining how they will decide who should get support services; these criteria must have been the subject of consultation and have been subjected to a rigorous assessment of their potential impact on disabled people as required by Equality Act 2010 s149.

The Common Assessment Framework for children and young people (CAF) is a shared assessment tool used across agencies in England. Some authorities have now developed this tool and it is also known as other names, such as Early Help Assessment. Its use can help

professionals develop a shared understanding of a child's needs, so they can be met more effectively. It will also avoid children and families having to tell and re-tell their story.

The CAF / Early Help Assessment is an important tool for preventative services. The Assessments have been designed specifically to help professionals assess needs at an earlier stage and then work with families, alongside other professionals and agencies, to meet them. The provision of early help services must take a pro-active approach to working with children and families. Efforts should be made to re-engage adolescent children to ensure they get support at the earliest opportunity.

The CAF / Early Help Assessment is not for when there is concern that a child may have been harmed or may be at risk of harm. In these circumstances the procedures set out in Part 3 of this Manual must be followed.

However, where a CAF / Early Help Assessment exists, it can provide useful information to assist with [Section 47 Enquiries](#) and other assessments.

Some children have important disadvantages that currently are only addressed when they become serious. Sometimes their parents know there is a problem but struggle to know how to get help.

The most important way of ensuring that these children can be identified earlier and helped before things reach crisis point is for everyone whose job involves working with children and families to keep an eye out for their well-being, and be prepared to help if something is going wrong.

The CAF / Early Help Assessment has been introduced to help do this. It is a tool to identify unmet needs. It covers all needs, not just the needs that individual services are most interested in.

## 5.5 Support needed

### What support do children and young people with epilepsy need from Social Care Services?

Epilepsy can impact on young people's education and social development in many different ways. Educationally, research shows that they can have cognitive, and behavioural problems that affects their learning. They can also suffer with mental health issues associated with their condition including anxiety and depression.

Socially, they may not feel confident to negotiate the normal day to day activities many children enjoy, because of their fear of having seizures and people's responses to this. They may have disabilities as a result of their epilepsy that mean they need additional support to communicate, travel, and socialise. Some young people with epilepsy can become socially isolated and may not have easy access to social groups with young people of their own age.

Parents may also need additional support both to understand how to help the child to manage the condition, but also to have the confidence to let their children develop independence because they feel so protective of their child as a result of their condition. Parents may also need respite support, including when their sleep is affected due to caring for a child who has

seizures at night. The condition can put a lot of additional stress on a family who may need extra support to manage.

The siblings of children with epilepsy may become young carers and this in turn can impact on their own opportunities to access social activities or even affect their education.

## 5.6 What should a 'good' service look like?

When a family seeks help or an assessment, this should be done in a timely way and involve the relevant professionals and family members to ensure that the full picture is understood. The views of the child should be sought wherever possible as part of the assessment and taken into consideration. Where a child has communication difficulties support should be given to enable them to express their views.

The assessment should inform the right plan for the child bringing together an integrated approach to their health education and social needs. The SEND Code states that: 'Local authorities should adopt a key working approach, which provides children, young people and parents with a single point of contact to help ensure the holistic provision and co-ordination of services and support'.

Models of service and the recommended roles for key workers vary, but central key worker tasks include:

- being the single point of contact for the family,
- the key source of information and guidance,
- the mediator and facilitator with other professionals across agency boundaries, and
- the coordinator of provision, as well as acting as an advocate and source of personal support.

An individual in this position is well placed not only to provide essential information but also to act as a guide through complex service structures, to take the strain of negotiation from the parents and to help them to access services. Key workers can be effective in relieving the stress often experienced by parents. The government has issued a range of guidance documents on the role of the 'lead professional'.

The SEND Code states further that 'EHC needs assessments should be combined with social care assessments under Section 17 of the Children Act 1989 where appropriate'.

Sadly, the impact of epilepsy is not always felt by families to be well understood within some professional networks, and therefore it is vital that professionals working with children with epilepsy have relevant information and training to better understand the condition.

## 6 Epilepsy and wellbeing

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Issues with wellbeing are common in young people with epilepsy and their parents, in particular that those with epilepsy experience significantly worse quality of life (QoL), defined as “an individual’s perception of their position in life, in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns”.

Research demonstrating the negative impact of epilepsy on specific quality of life measures has been shown repeatedly, and it also appears to be worse when compared with other, comparable long-term conditions such as asthma and diabetes.

This section will cover some of the main factors influencing this effect.

### 6.1 Behavioural and learning impact

The cognitive effects of epilepsy have been found to contribute significantly to lower quality of life. A Young Epilepsy study found that 95% of school-aged children had a significant difficulty in at least one area of learning or behaviour. For example:

- 60% of school children with epilepsy have a behavioural disorder;
- 58% have memory underachievement;
- 42% underachieve in the area of processing speed;
- 42% underachieve in at least one academic area (e.g. mathematics and comprehension).

Although not an automatic consequence of the condition, CYP with epilepsy are certainly at greater risk of learning and behavioural difficulties than those without. This risk may be attributed to:

- the effects of epilepsy itself on the brain (whether active seizures or as an underlying condition);
- psychosocial issues linked to having epilepsy.
- on occasion, medication side effects.

As a result, those providing care for CYP with epilepsy should look to screen for behavioural and learning issues; a number of tools are available for this purpose (e.g. ABLE tool).

### 6.2 Emotional well-being

Anxiety and depression in young people with epilepsy have been shown to have a deleterious effect on quality of life, an impact independent of other associated factors. A similar effect has also been demonstrated on parents of young people with the condition.

As such, it is vital that those providing care are vigilant regarding signs of anxiety and depression, particularly as intervention at an early stage can positively influence the course and, hence, impact on QoL. Professionals should look to formal screening measures to identify needs.

### 6.3 Stigma and discrimination

Young people with epilepsy undoubtedly experience discrimination due to both stigma and lack of awareness about their condition. Indeed, the fear of stigma itself can adversely impact on QoL; this has also been demonstrated in the wellbeing of parents, for example with fear of bullying. Again, the onus is on professionals to help address such issues by sensitively enquiring and appropriately supporting.

### 6.4 The role of self-management

There is an increasing trend in the NHS for people with long-term conditions to be given the tools to self-manage their condition. This equally applies to CYP with epilepsy, and the potential impact on wellbeing is apparent. For example:

- Adopting a healthy lifestyle (e.g. a good diet, exercise, avoiding stress) will help in limiting common seizure triggers, as well as promoting wellbeing generally.
- Awareness of individual seizure triggers will empower young people to self-care for these aspects of their life (e.g. moderating social activities and/or recovery to minimise sleep deprivation).
- Knowledge about risks and benefits of concordance with anti-epileptic medication at an early age will encourage sensible self-management.

Professionals should therefore look to encourage self-management wherever possible, to help ensure young people are adequately informed about their condition, able to maximise healthy independence in their lives, and so optimise wellbeing.

## 7 Learning disabilities

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One size does not fit all in terms of accessing healthcare and providers must legally make adjustments to care to ensure individuals with disabilities can access the healthcare they require. The Equality Act (2010) clearly sets this out in terms of the need to make reasonable adjustments. In this section, reasonable care adjustments are highlighted, that can be adapted and used for a variety of individuals as long as they are tailored to meet their needs.

### 7.1 Diagnostic overshadowing

Diagnostic overshadowing occurs when a health professional makes the assumption that a person with a learning (and or other) disability's behaviour is a part of their disability - without exploring other factors such as biological determinants.

At times health professionals can fall into this trap, which causes a great deal of difficulties for people with and without a learning disability, who may have other disabilities or health issues including epilepsy, that mean the focus too frequently centres around these as opposed to exploring other reasons. Diagnostic overshadowing is particularly pertinent when new behaviours develop or existing ones increase.

Given that people with learning disabilities have a much higher risk of experiencing a variety of diseases and conditions, it is vital that physiological or pathological determinants in behaviour change are explored. If they are not, people with learning disabilities can suffer poor care.

### 7.2 Key points to eliminate diagnostic overshadowing

- **Be respectful.** Don't make assumptions about a person's quality of life. Treat the patient in a way that is appropriate to their chronological age
- **Respect confidentiality,** as for any other patient
- **Always communicate with the patient directly.** If a person does not use verbal language to communicate, use pictures like the ones in the Books Beyond Words series, photos, symbols, and signs to engage with them
- **Assess people's health and wellbeing** so that any changes in behaviour that may signify changes in condition or an illness are not attributed to their learning disability
- **Pay close attention to non-verbal communication,** for example sounds, body positions, facial gestures and other non-verbal signs that may indicate pain, anxiety and discomfort
- **Be aware of the physical setting** and how you can adjust it to support the patient's access, comfort and safety
- **Understand the issues around gaining consent** clearly, and make every effort to gain consent

- **Seek out help from people who know the patient** best and engage with family or supporters to help you communicate effectively with them. This may help you get to know the person and understand what is in their best interests if they lack capacity to consent
- **Ensure that the lines of communication with the patient, their family carers, advocates or supporters are clearly established** throughout the healthcare journey
- **Always liaise with Community Learning Disability Team colleagues** such as community learning disability nurses and other community health professionals to support admission and discharge for hospital, or if someone with a learning disability does not turn up for an appointment.

Given that each person is different, and a one size fits all approach is not appropriate, a useful tool to consider when making care adjustments is as follows:

**Time** – take time to work with the patient

**Environment** – alter the environment e.g. quieter areas, reduce lighting and waiting

**Attitude** – have a positive solution orientated focus

**Communication** – find out the best way to communicate with the patient and also communicate this to colleagues

**Help** – what help does the patient need and how can you meet their needs

(The **TEACH** approach was adapted from the one created by Hertfordshire Community Learning Disability Team)

Taking a TEACH approach should ensure that the care prescribed is more likely to be successfully implemented in a manner that fits the person's requirements. There are numerous ways that care can be delivered creatively to ensure better care experiences and outcomes, such as the ones below:

**Offering the first or last appointment** when attending an outpatient appointment

**Offering a double appointment**, so there is more time to enable participation in the consultation

**Providing a 'hospital passport'** to facilitate communication

**Making information accessible** by using a communication book, photographs, signs, symbols and jargon free language

**Making changes to the environment** e.g. altering lighting, seeking quieter places, calmer waiting /clinic areas, buzzers to ensure those who find waiting hard can go off site and wait and then be 'called' back when it is their turn for their appointment

**Involving the child / young person and their families/ carers** in the decision making process around care, treatment and discharge home

## 7.3 How hospital passports change care

- Filled in by the person with a learning disability or family/supporters
- Provide a complete view of the person
- Not just about ill health
- Owned by the individual
- Personalises and dignifies care
- Enhances patient safety by providing information about a person who may not otherwise be able to tell health professionals

This is my **Hospital Passport**  

For people with learning disabilities coming into hospital

My name is:   
I like to be called:

If I have to go to hospital this book needs to go with me, it gives hospital staff important information about me.

It needs to hang on the end of my bed and a copy should be put in my notes.

This passport belongs to me. Please return it when I am discharged.

Nursing and medical staff please look at my passport before you do any interventions with me.





**Mental Capacity Act 2005**

If I am assessed as lacking the capacity to consent to my treatment the following people must be involved in best interest decision making

|      |              |                 |
|------|--------------|-----------------|
| Name | Relationship | Contact Details |

## 7.4 How healthcare and support workers can help

### How healthcare and support workers can get things right for people with a learning disability accessing healthcare

- **Beware of missing serious illness** – don't ignore medical symptoms by assuming they are part of the person's disability. Act quickly!
- **Find the best way to communicate** – with the person, their families, carers, friends. Not everyone speaks, so use photos, signs, symbols, accessible publications such as the Books Beyond Words series, and pictures alongside speech.
- **The person, their family and carers are experts** – they can help interpret signs and behaviours that may show distress or pain.
- **Read and act on the hospital or health passport** – these provide vital information about a person's needs.

- **Assessing someone's capacity to consent** to treatment is dependent on time, decision and topic.
- **Make reasonable adjustments** – for example, by finding someone a quieter place to wait and to be seen in, or by minimising waiting times

## 8 Commissioning context

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A number of resources are available to help support in the commissioning of epilepsy services, with the following examples of particular use:

### Commissioning toolkit

The Epilepsy Society have developed a commissioning toolkit, which collates information and resources such as an audit checklist, business cases and case studies

<http://www.epilepsytoolkit.org.uk/>

### Commissioning guide

'[Better value, better care](#)' from Epilepsy Action looks at why epilepsy care services should be commissioned and what effective commissioning involves.

<https://www.epilepsy.org.uk/sites/epilepsy/files/primary-care-resource/epilepsyaction-primary-care-commissioning-book.pdf>

### Service specification

Children's epilepsy surgery is commissioned by NHS England specialised commissioning

<https://www.england.nhs.uk/publication/childrens-epilepsy-surgery-service-cess/>

### NICE Quality Standard

As with all NICE quality standards, this sets out the priority areas for improving quality in CYP epilepsy services.

<https://www.nice.org.uk/guidance/qs27/resources>

### Commissioning and budgeting tools

Alongside the epilepsy Quality Standard, NICE also developed tools to help commissioners

<https://www.nice.org.uk/guidance/qs27/resources/services-for-the-diagnosis-and-management-of-the-epilepsies-in-adults-children-and-young-people-commissioning-guide-317820637/chapter/6-The-commissioning-and-budgeting-tools>

### Epilepsy12

The national audit for childhood epilepsy has the continued aim of helping epilepsy services, and those who commission services, to measure and improve the quality of care for CYP with epilepsy. <https://www.rcpch.ac.uk/epilepsy12>

### Best practice tariff (BPT)

The BPT is a payment for each attendance for follow-up appointments and covers outpatient care after first acute or outpatient assessment, for patients with a diagnosis of probable epilepsy until they transfer to adult services. Activity that meets the best practice criteria must be coded against the TFC 223 Paediatric Epilepsy.

The BPT is payable to providers of a service that meets these criteria:

- a) Paediatric consultants with expertise in epilepsies lead the service, with epilepsy specialist nurses (ESN) performing an integral role.
- b) Patients have a comprehensive care plan agreed between the patient, family and/or carers and both the paediatric consultant with expertise in epilepsies and the ESN. This must cover lifestyle issues as well as medical issues.
- c) Follow-up appointments provide sufficient time with both the paediatric consultant (or associate specialist) with expertise in epilepsies and the ESN to manage the patient against the agreed care plan. As a guide, it is expected that the patient spends at least 20 minutes with each professional (either at the same time or in successive slots). All children with epilepsy must be able to be reviewed when clinically required. Outpatient booking systems must be able to guarantee these follow-up appointments.
- d) The service has evidence of shared care and referral pathways to tertiary paediatric neurology services, transition and referral pathways to adult services, and continuing full participation in the Epilepsy 12 national audit.

It does *not* include costs related to:

- acute inpatient care
- new patient assessment
- epilepsy investigation and treatment costs (eg electroencephalography, magnetic resonance imaging, drugs, surgery, vagal nerve stimulation, ketogenic diet, etc) with the exception of the costs of blood tests
- the costs of the more complex epilepsy patients who, in line with NICE guidelines, have shared care with a paediatric neurologist and are coded to the paediatric neurology TFC; it is anticipated that about one third of epilepsy patients fall into this category
- costs of child and adolescent mental health services (CAMHS), other therapists, etc
- costs of assessment and treatment for other health problems.

## 9 Glossary

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AEDs – Antiepileptic drugs

BNFC – British National Formulary for children

CAMHS – Child and adolescent mental health services

CCG – Clinical Commissioning Group

CESS – Children’s Epilepsy Surgery Service (in England)

CYP – Children and young people

CYPF – children, young people and families

ECG – Electrocardiogram

EEG – Electroencephalogram

ED – Emergency Department

ESN – Epilepsy specialist nurse

Hypoxia - a condition in which the body or a region of the body is deprived of adequate oxygen supply at the tissue level

IHP – Individual healthcare plan

ILAE – International League Against Epilepsy

MRI Magnetic Resonance Imaging

NES - Non epileptic seizures

NICE – National Institute for Clinical Excellence

NTPEN – North Thames Paediatric Epilepsy Network

SETPEG – South East Thames Paediatric Epilepsy Group

SUDEP - Sudden unexpected death in epilepsy

STP – Strategic Transformation Partnerships

VNS – Vagal Nerve stimulation

## 10 Useful websites and other resources

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**Beyond Words:** [www.booksbeyondwords.co.uk](http://www.booksbeyondwords.co.uk) stories in pictures to help people with learning disabilities and communication disabilities explore and understand their own experiences

**Easy Health:** [www.esayhealth.org.uk](http://www.esayhealth.org.uk) accessible health information

**Intellectual disability and health (University of Hertfordshire):** [www.intellectualdisability.info](http://www.intellectualdisability.info) health information for health professionals about people with learning disabilities

**www.mencap.org.uk/gettingitright** getting it right when treating people with a learning disability

**Well at school:** <http://www.wellatschool.org/epilepsy>

**Epilepsy Action:** <https://www.epilepsy.org.uk/>

**Young Epilepsy:** [www.youngepilepsy.org.uk](http://www.youngepilepsy.org.uk)

## B) Care Standards

|                     | Area of care    | Standard   | Measurement Criteria/<br>Demonstration of<br>Compliance  | Source  |
|---------------------|-----------------|--|--|---|
| <b>PRIMARY CARE</b> |                 |  |  |   |
| 1                   | Pathway of care | Children and young people presenting with a suspected seizure are seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation.   | <ul style="list-style-type: none"> <li>Evidence of local arrangements/referral pathway, (e.g. via telephone referral, urgent e-referral)</li> <li>Case note audit</li> </ul> | NICE (2013) Epilepsy in children and young people (Quality Standard QS27) |
| 2                   | Medication      | When it has been initiated by a specialist, continue to issue prescribed emergency care and treatment to children and young people who have prolonged (lasting 5 minutes or more) or repeated (three or more in an hour) convulsive seizures in the community. | <ul style="list-style-type: none"> <li>Evidence of continuing supply (e.g. repeat prescriptions)</li> </ul>  | NICE (2012) Epilepsies: diagnosis and management (CG137)                  |
| 3                   | Review          | Children and young people with epilepsy should be registered with a general medical practice. Prescription and therapies should be continued as per the CYP's shared care plan from secondary and/or tertiary care.  | <ul style="list-style-type: none"> <li>Case note audit (i.e. evidence of actions as per shared care plan)</li> </ul>   | NICE (2012) Epilepsies: diagnosis and management (CG137)                  |

|  | Area of care       | Standard   | Measurement Criteria/<br>Demonstration of<br>Compliance  | Source  |
|--|--------------------|--|--|---|
| <b>SECONDARY/TERTIARY CARE</b>   |                    |  |  |   |
| <b>1) CYP with suspected seizures should be seen promptly and investigated appropriately, in accordance with current NICE guidance</b>         |                    |  |  |   |
| <b>2) CYP with epilepsy should be referred for tertiary care assessment in accordance with NICE guidance</b>                                   |                    |  |  |   |
| <b>3) CYP with epilepsy should receive at least annual review, or sooner if clinically indicated, in accordance with current NICE guidance</b> |                    |  |  |   |
| 4  | Pathway of care    | Children and young people presenting with a suspected seizure are seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation. | <ul style="list-style-type: none"> <li>Evidence of local arrangements/referral pathway, (e.g. via telephone referral, urgent e-referral)</li> <li>Case note audit</li> </ul> | NICE (2013) Epilepsy in children and young people (Quality Standard QS27) |
| 5  | Diagnostic pathway | Children and young people have initial investigations for epilepsy within 4 weeks of them being requested  | <ul style="list-style-type: none"> <li>Evidence of local arrangements/pathway</li> <li>Case note audit</li> </ul>  | NICE (2013) Epilepsy in children and young people (Quality Standard QS27) |
| 6  | Investigations     | Children and young people who meet the criteria for neuroimaging for epilepsy have magnetic resonance imaging.   | <ul style="list-style-type: none"> <li>Evidence of local arrangements/pathway</li> <li>Case note audit</li> </ul>  | NICE (2013) Epilepsy in children and young people (Quality Standard QS27) |
| 7  | Investigations     | Children and young people requiring MRI should have the test performed soon.   | <ul style="list-style-type: none"> <li>Evidence of local arrangements/pathway</li> <li>Case note audit</li> </ul>  | NICE (2012) Epilepsies: diagnosis and management (CG137)                  |

|    | Area of care   | Standard   | Measurement Criteria/<br>Demonstration of<br>Compliance   | Source  |
|----|----------------|--|---|---|
| 8  | Investigations | Children and young people requiring an EEG should have the test performed soon after it has been requested.  | <ul style="list-style-type: none"> <li>Evidence of local arrangements/pathway</li> <li>Case note audit</li> </ul> | NICE (2012) Epilepsies: diagnosis and management (CG137)                  |
| 9  | Review         | The diagnosis of epilepsy needs to be critically evaluated if events continue despite an optimal dose of a first-line AED.   | Case note audit   | NICE (2012) Epilepsies: diagnosis and management (CG137)                  |
| 10 | Review         | Children and young people with epilepsy have a structured review with a paediatric epilepsy specialist at least annually   | <ul style="list-style-type: none"> <li>Evidence of local arrangements/pathway</li> <li>Case note audit</li> </ul> | NICE (2013) Epilepsy in children and young people (Quality Standard QS27) |
| 11 | Review         | Children and young people with epilepsy are seen by an epilepsy specialist nurse who they can contact between scheduled reviews.   | <ul style="list-style-type: none"> <li>Evidence of local arrangements/pathway</li> <li>Case note audit</li> </ul> | NICE (2013) Epilepsy in children and young people (Quality Standard QS27) |
| 12 | Review         | For children and young people, the maximum interval between reviews should be 1 year, but the frequency of reviews should be determined by the child or young person's epilepsy and their wishes and those of the family and/or carers. The interval between reviews should be agreed between the child or young person, their family and/or carers as appropriate, and the specialist, but is likely to be between 3 and 12 months. | <ul style="list-style-type: none"> <li>Case note audit</li> </ul>   | NICE (2012) Epilepsies: diagnosis and management (CG137)                  |
| 13 | Review         | If the structured review is to be conducted by the specialist, this may be best provided in the context of a specialist epilepsy clinic.   | <ul style="list-style-type: none"> <li>Evidence of local arrangements/pathway</li> </ul>                          | NICE (2012) Epilepsies: diagnosis and management (CG137)                  |
| 14 | Review         | Treatment should be reviewed at regular intervals to ensure that children and young people with epilepsy are not maintained for long periods on treatment that is ineffective or poorly tolerated and that concordance with prescribed medication is maintained.   | <ul style="list-style-type: none"> <li>Case note audit</li> </ul>   | NICE (2012) Epilepsies: diagnosis and management (CG137)                  |

|    | Area of care | Standard  | Measurement Criteria/<br>Demonstration of<br>Compliance   | Source  |
|----|--------------|---|---|---|
| 15 | Transition   | Young people with epilepsy have an agreed transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services. Services should aim to follow "Transition to adult services" standards from HLP's London Acute Care Standards for Children and Young People"<br><a href="https://www.healthylondon.org/resource/acute-care-standards-children-young-people/">https://www.healthylondon.org/resource/acute-care-standards-children-young-people/</a> | <ul style="list-style-type: none"> <li>Evidence of local arrangements/pathway</li> </ul>  | NICE (2013) Epilepsy in children and young people (Quality Standard QS27)<br>Healthy London Partnership<br><a href="#">Acute care standards</a> |
| 16 | Referral     | In cases of diagnostic uncertainty, consider cardiac causes   | <ul style="list-style-type: none"> <li>Case note audit</li> </ul>   | NICE (2012) Epilepsies: diagnosis and management (CG137)  |
| 17 | Referral     | Information regarding a CYP's epilepsy should be shared, with appropriate consent, with schools if learning concerns are present (via the school nurse and/or SENCO), so that adequate assessment and support strategies can be considered.   | <ul style="list-style-type: none"> <li>Case note audit (i.e. clear documentation of learning concerns in correspondence, and of decision to share information)</li> </ul> | NICE (2012) Epilepsies: diagnosis and management (CG137)<br>CHES study (Children with Epilepsy in Sussex Schools) (2014) Young Epilepsy         |
| 18 | Referral     | Referral for a neurodevelopmental/ cognitive assessment is indicated: <ul style="list-style-type: none"> <li>- when a CYP with epilepsy is having developmental/ educational or occupational difficulties,</li> <li>- when an MRI has identified abnormalities in cognitively important brain functions</li> <li>- when a CYP complains of memory or other cognitive deficits and/or decline.</li> </ul>  | <ul style="list-style-type: none"> <li>Evidence of local arrangements/pathway</li> <li>Case note audit</li> </ul>   | NICE (2012) Epilepsies: diagnosis and management (CG137)  |

|    | Area of care                  | Standard   | Measurement Criteria/<br>Demonstration of<br>Compliance   | Source  |
|----|-------------------------------|--|---|---|
| 19 | Referral to tertiary services | Children and young people who meet the criteria for referral to a tertiary care specialist are seen (or discussed) within 4 weeks of referral.   | <ul style="list-style-type: none"> <li>Evidence of local arrangements/pathway</li> <li>Case note audit</li> </ul>             | NICE (2013) Epilepsy in children and young people (Quality Standard QS27) |
| 20 | Referral to tertiary services | <p>Referral should be considered when one or more of the following criteria are present:</p> <ul style="list-style-type: none"> <li>the epilepsy is not controlled with medication within 2 years</li> <li>management is unsuccessful after two drugs</li> <li>the child is aged under 2 years</li> <li>a child or young person experiences, or is at risk of, unacceptable <ul style="list-style-type: none"> <li>side effects from medication</li> <li>there is a unilateral structural lesion</li> <li>there is psychological and/or psychiatric co-morbidity</li> <li>there is diagnostic doubt as to the nature of the seizures and/or seizure syndrome.</li> </ul> </li> </ul> | <ul style="list-style-type: none"> <li>Evidence of regional arrangements/referral pathway</li> <li>Case note audit</li> </ul> | NICE (2012) Epilepsies: diagnosis and management (CG137)                  |
| 21 | Referral to tertiary services | In children, the diagnosis and management of epilepsy within the first few years of life may be extremely challenging. For this reason, children with suspected epilepsy should be referred to tertiary services early, because of the profound developmental, behavioural and psychological effects that may be associated with continuing seizures.  | <ul style="list-style-type: none"> <li>Evidence of regional arrangements/referral pathway</li> <li>Case note audit</li> </ul> | NICE (2012) Epilepsies: diagnosis and management (CG137)                  |
| 22 | Referral to tertiary services | Behavioural or developmental regression, stasis or slowing of developmental progress, or inability to identify the epilepsy syndrome in a child or young person, should result in immediate  | <ul style="list-style-type: none"> <li>Evidence of regional arrangements/referral pathway</li> </ul>                          | NICE (2012) Epilepsies: diagnosis and management (CG137)                  |

|                       | Area of care                  | Standard   | Measurement Criteria/<br>Demonstration of<br>Compliance   | Source   |
|-----------------------|-------------------------------|--|---|--|
|                       |                               | referral to tertiary services.   | <ul style="list-style-type: none"> <li>Case note audit</li> </ul>   |  |
| 23                    | Referral to tertiary services | Children and young people with specific syndromes such as Sturge–Weber syndrome, the hemispheric syndromes, Rasmussen's encephalitis and hypothalamic hamartoma should be referred to a tertiary epilepsy service.                     | <ul style="list-style-type: none"> <li>Evidence of regional arrangements/referral pathway</li> <li>Case note audit</li> </ul> | NICE (2012) Epilepsies: diagnosis and management (CG137) |
| 24                    | Referral to tertiary services | Psychiatric co-morbidity and/or negative baseline investigations should not be a contraindication for referral to a tertiary service.  | <ul style="list-style-type: none"> <li>Evidence of regional arrangements/referral pathway</li> <li>Case note audit</li> </ul> | NICE (2012) Epilepsies: diagnosis and management (CG137) |
| <b>Investigations</b> |                               |  |   |  |
| 25                    | Neuroimaging                  | MRI should be the imaging investigation of choice in children and young people with epilepsy, using appropriate imaging protocols and sedation/anaesthesia in order to achieve optimal imaging   | <ul style="list-style-type: none"> <li>Case note audit</li> </ul>   | NICE (2012) Epilepsies: diagnosis and management (CG137) |
| 26                    | Neuroimaging                  | MRI should be a routine investigation in CYP with epilepsy, except where there is a diagnosis of idiopathic generalised epilepsy or where there is clear evidence of benign focal epilepsy   | <ul style="list-style-type: none"> <li>Case note audit</li> </ul>   | NICE (2012) Epilepsies: diagnosis and management (CG137) |
| 27                    | Other Tests                   | In children and young people, other investigations, including blood and urine biochemistry, should be undertaken at the discretion of the specialist to exclude other diagnoses, and to determine an underlying cause of the epilepsy. | <ul style="list-style-type: none"> <li>Case note audit</li> </ul>   | NICE (2012) Epilepsies: diagnosis and management (CG137) |

|    | Area of care | Standard  | Measurement Criteria/<br>Demonstration of<br>Compliance   | Source   |
|----|--------------|---|---|--|
| 28 | Other Tests  | In children and young people, a 12-lead ECG should be considered in cases of diagnostic uncertainty.  | <ul style="list-style-type: none"> <li>Case note audit</li> </ul>   | NICE (2012) Epilepsies: diagnosis and management (CG137) |
| 29 | EEG          | <p>Regarding use of EEG</p> <ul style="list-style-type: none"> <li>EEG should be performed only to support a diagnosis of epilepsy in children and young people.</li> <li>if considered necessary, EEG should be performed after the second epileptic seizure but may, in certain circumstances, as evaluated by the specialist, be considered after a first epileptic seizure.</li> <li>EEG may be used to help determine seizure type and epilepsy syndrome in children and young people in whom epilepsy is suspected. This enables them to be given the correct prognosis.</li> <li>EEG can be used to assess the risk of seizure recurrence in CYP presenting with a first unprovoked seizure, unequivocal epileptiform activity shown on EEG.</li> <li>repeated standard EEGs may be helpful when the diagnosis of the epilepsy or the syndrome is unclear. However, if the diagnosis has been established, repeat EEGs are not likely to be helpful.</li> <li>repeated standard EEGs should not be used in preference to sleep or sleep-deprived EEGs.</li> <li>a sleep EEG is best achieved through sleep deprivation or the use of melatonin.</li> <li>Long-term video or ambulatory EEG may be used in the</li> </ul> | <ul style="list-style-type: none"> <li>Evidence of regional arrangements/referral pathway</li> <li>Case note audit</li> </ul> | NICE (2012) Epilepsies: diagnosis and management (CG137) |

|    | Area of care   | Standard   | Measurement Criteria/<br>Demonstration of<br>Compliance             | Source   |
|----|--|--|---|--|
|    |  | <p>assessment of children and young people who present diagnostic difficulties after clinical assessment and standard EEG.</p> <ul style="list-style-type: none"> <li>• Photic stimulation and hyperventilation should remain part of may induce a seizure and they have a right to refuse.</li> <li>• The child and young person and family and/or carer should be made aware that such activation procedures are part of standard EEG assessment.</li> </ul> |   |  |
|    | <p><b>4) CYP with epilepsy should have their seizure/event types described accurately in documentation</b></p> <p><b>5) CYP with epilepsy should have their epilepsy classified using the latest ILAE framework and, where appropriate, a precise electroclinical syndrome</b></p> |  |   |  |
|    | <p><b>Classification</b></p>   |  |   |  |
| 30 |  | <p>Epileptic seizures and epilepsy syndromes in children and young people should be classified using a multi-axial diagnostic scheme. This should include: description of seizure, seizure type, syndrome, aetiology and co-morbidities.</p>   | <ul style="list-style-type: none"> <li>• Case note audit</li> </ul> | <p>NICE (2012) Epilepsies: diagnosis and management (CG137)<br/>2017 ILAE Seizure Classification</p> |
| 31 |  | <p>Seizure classification should be supported by:</p> <ul style="list-style-type: none"> <li>• Eliciting symptoms and signs of event (semiology)</li> <li>• Looking for familiar patterns suggesting an electroclinical syndrome</li> <li>• Using ancillary data where indicated, e.g, EEG, MRI, genes, antibodies, etc</li> </ul>   | <ul style="list-style-type: none"> <li>• Case note audit</li> </ul> | <p>2017 ILAE Seizure Classification</p>  |

|    | Area of care   | Standard   | Measurement Criteria/<br>Demonstration of<br>Compliance           | Source   |
|----|--|--|---|--|
|    | <b>6) Where warranted, anti-epileptic drug treatment should be commenced in line with NICE guidance or other up-to-date, evidence-based practice. Appropriate formulations should be considered in order to optimise concordance</b> |  |   |  |
| 32 | Treatment  | Consistent supply to the child and young person with epilepsy of a particular manufacturer's AED preparation is recommended (unless the prescriber, in consultation with the CYP, and their family and/or carers) considers this is not a concern).  | <ul style="list-style-type: none"> <li>Case note audit</li> </ul> | NICE (2012) Epilepsies: diagnosis and management (CG137) |
| 33 | Drug therapy   | It is recommended that children and young people should be treated with a single AED (monotherapy) wherever appropriate. If the initial treatment is unsuccessful, then monotherapy using another drug can be tried. Caution is needed during the changeover period.   | <ul style="list-style-type: none"> <li>Case note audit</li> </ul> | NICE (2012) Epilepsies: diagnosis and management (CG137) |
| 34 | Drug therapy   | If an AED has failed because of adverse effects or continued seizures, a second drug should be started (which may be an alternative first-line or second-line drug) and built up to an adequate or maximum tolerated dose and the first drug may be tapered off slowly.  | <ul style="list-style-type: none"> <li>Case note audit</li> </ul> | NICE (2012) Epilepsies: diagnosis and management (CG137) |
| 35 | Drug therapy   | It is recommended that combination therapy (adjunctive or 'add-on' therapy) should only be considered when attempts at monotherapy with AEDs have not resulted in seizure freedom. If trials of combination therapy do not bring about worthwhile benefits, treatment should revert to the regimen (monotherapy or combination therapy) that has proved most acceptable to the child or young person, in terms of providing the best balance between effectiveness in reducing seizure frequency and tolerability of side effects. | <ul style="list-style-type: none"> <li>Case note audit</li> </ul> | NICE (2012) Epilepsies: diagnosis and management (CG137) |

|    | Area of care                  | Standard   | Measurement Criteria/<br>Demonstration of<br>Compliance   | Source   |
|----|-------------------------------|--|---|--|
| 36 | Drug therapy                  | <p>Regarding use of valproate</p> <ul style="list-style-type: none"> <li>Do not prescribe valproate for in girls unless other treatments are ineffective or not tolerated</li> <li>If prescribing valproate, ensure women and girls taking valproate medicines understand the 30 – 40% risk of neurodevelopmental disorders and 10% risk of birth defects and are using effective contraception</li> <li>Valproate use in girls of childbearing potential must be initiated and supervised by specialists</li> </ul> | <ul style="list-style-type: none"> <li>Case note audit</li> </ul>   | MHRA (2017)  |
| 37 | Psychological therapy         | Psychological interventions (relaxation, cognitive behaviour therapy) may be effective in children and young people with epilepsy, especially drug-resistant focal epilepsy.   | <ul style="list-style-type: none"> <li>Case note audit</li> </ul>   | NICE (2012) Epilepsies: diagnosis and management (CG137) |
| 38 | Non-drug therapy              | Refer children and young people with epilepsy whose seizures have not responded to appropriate AEDs to a tertiary paediatric epilepsy specialist for consideration of the use of a ketogenic diet.   | <ul style="list-style-type: none"> <li>Evidence of regional arrangements/referral pathway</li> <li>Case note audit</li> </ul> | NICE (2012) Epilepsies: diagnosis and management (CG137) |
| 39 | Vagal nerve stimulation (VNS) | Vagal nerve stimulation is indicated for use as an adjunctive therapy in reducing the frequency of seizures in children and young people who are refractory to antiepileptic medication but who are not suitable for resective surgery. This includes children and young people whose epileptic disorder is dominated by focal seizures (with or without secondary generalisation) or generalised seizures   | <ul style="list-style-type: none"> <li>Evidence of regional arrangements/referral pathway</li> <li>Case note audit</li> </ul> | NICE (2012) Epilepsies: diagnosis and management (CG137) |

|    | Area of care   | Standard   | Measurement Criteria/<br>Demonstration of<br>Compliance           | Source  |
|----|----------------|--|---|---|
| 40 | Drug therapy   | <p>Regarding rescue medication:</p> <ul style="list-style-type: none"> <li>only prescribe buccal midazolam (or rectal diazepam) for CYP who have had a previous episode of prolonged or serial convulsive seizures, if initiated by a specialist as part of a care plan</li> <li>review and removal of previously prescribed buccal midazolam is needed annually</li> <li>treatment should be administered by trained clinical personnel or, if specified by an individually agreed protocol drawn up with the specialist, by family members or carers with appropriate training.</li> </ul> | <ul style="list-style-type: none"> <li>Case note audit</li> </ul> | NICE (2012) Epilepsies: diagnosis and management (CG137)  |
| 41 | Emergency care | Care must be taken to secure the child and young person airway and assess his or her respiratory and cardiac function.   | <ul style="list-style-type: none"> <li>Case note audit</li> </ul> | NICE (2012) Epilepsies: diagnosis and management (CG137)  |
| 42 | Emergency care | Emergency treatment of prolonged seizures or status epilepticus should be via agreed local protocols (based on APLS guidelines or other evidence-based guidelines), unless an individualised emergency care plan has been written with a specialist  | <ul style="list-style-type: none"> <li>Case note audit</li> </ul> | NICE (2012) Epilepsies: diagnosis and management (CG137)<br>Advanced Paediatric Life Support (2016) 6th Edition, ALSG |

|    | Area of care   | Standard   | Measurement Criteria/<br>Demonstration of<br>Compliance           | Source  |
|----|----------------|--|---|---|
| 43 | Drug therapy   | <p>Regarding females of child-bearing age:</p> <ul style="list-style-type: none"> <li>all women and girls on AEDs should be offered 5 mg per day of folic acid before any possibility of pregnancy</li> </ul> <p>If taking an enzyme-inducing AED:</p> <ul style="list-style-type: none"> <li>The progestogen-only pill is not recommended as reliable contraception</li> <li>The progestogen implant is not recommended</li> <li>The use of additional barrier methods should be discussed</li> <li>If emergency contraception is required, the type and dose of emergency contraception should be in line with the SPC and current edition of the BNF for children.</li> </ul> | <ul style="list-style-type: none"> <li>Case note audit</li> </ul> | NICE (2012) Epilepsies: diagnosis and management (CG137)  |
| 44 | Surgical       | Units should comply with CESS guidance when considering epilepsy surgery   | <ul style="list-style-type: none"> <li>Case note audit</li> </ul> | Epilepsy Action and NHS England A guide for Paediatricians: Children's Epilepsy Surgery Service (CESS) Guidelines for children's epilepsy brain surgery referrals in England          |
| 45 | Ketogenic diet | Both new and current medications should be evaluated if a child or young person is on the ketogenic diet, such that the most compatible formulation and brand is selected. If in any doubt, the ketogenic diet team should be contacted for advice.  | <ul style="list-style-type: none"> <li>Case note audit</li> </ul> | SET PEG website - Guys and St Thomas's Trust<br><a href="http://www.setpeg.co.uk/guidelines/ketogenic-diet-medicines">http://www.setpeg.co.uk/guidelines/ketogenic-diet-medicines</a> |

|  | Area of care  | Standard  | Measurement Criteria/<br>Demonstration of<br>Compliance   | Source   |
|--|---------------|---|---|--|
| <b>CARE PLANNING</b>   |               |   |   |  |
| <p><b>7) CYP with epilepsy should have an appropriate individualised care plan, drawn up in conjunction with the young person/family, and input from any other relevant professionals providing care. This should include what to do in the event of a seizure (especially prolonged seizures), as well as other tailored advice for that individual young person. It should be reviewed annually (or sooner if changes are warranted)</b></p> <p><b>8) Permission should be sought to share documentation with the child/young person’s school/college and other relevant professionals (e.g. social worker, mental health professional), to encourage joined-up care</b></p> |               |   |   |  |
| 46   | Care planning | Children and young people with a history of prolonged or repeated seizures have an agreed written emergency care plan.  | <ul style="list-style-type: none"> <li>Evidence of local arrangements</li> <li>Case note audit</li> </ul> | NICE (2013) Epilepsy in children and young people (Quality Standard QS27)<br>RCPCH Epilepsy Passport (2015) Epilepsy Action Plan |
| 47   | Care planning | Every child with epilepsy should have an individual healthcare plan. This should include what to do in the event of a seizure (and especially prolonged seizures), as well as other tailored advice for that individual young person. This should be comprehensive and agreed between the young person, family and/or carers where appropriate, plus primary care and secondary care providers. This should include lifestyle issues as well as medical issues. | <ul style="list-style-type: none"> <li>Evidence of local arrangements</li> <li>Case note audit</li> </ul> | Healthy London Partnership - Epilepsy guide for schools  |
| 48   | Care planning | An individual treatment pathway should be formulated for children and young people who have recurrent convulsive status epilepticus.  | <ul style="list-style-type: none"> <li>Case note audit</li> </ul>   | NICE (2012) Epilepsies: diagnosis and management (CG137)   |

|  | Area of care    | Standard  | Measurement Criteria/<br>Demonstration of<br>Compliance              | Source   |
|--|-----------------|---|--|--|
| <b>HOLISTIC CARE</b>   |                 |   |  |  |
| <p><b>9) CYP with epilepsy should have the functional impact of their epilepsy (including mental health, wellbeing, education and quality of life) regularly assessed and documented, regardless of seizure control</b></p> <p><b>10) Appropriate safety and lifestyle advice should be given to every CYP with epilepsy, both at diagnosis and also at regular intervals</b></p> <p><b>11) Every interaction with a CYP with epilepsy should be appropriately inclusive and accessible, based on the individual's needs</b></p> |                 |   |  |  |
| 49   | Decision making | Healthcare professionals should adopt a consulting style that enables the child or young person with epilepsy, and their family and/or carers as appropriate, to participate as partners in all decisions about their healthcare, taking fully into account any specific needs. | <ul style="list-style-type: none"> <li>• Patient feedback</li> </ul> | NICE (2012) Epilepsies: diagnosis and management (CG137) |
| 50   | Self-management | Children and young people with epilepsy and their families and/or carers should be empowered to manage their condition as well as possible.   | <ul style="list-style-type: none"> <li>• Patient feedback</li> </ul> | NICE (2012) Epilepsies: diagnosis and management (CG137) |
| 51   | Self-management | In children and young people, self-management of epilepsy may be best achieved through active child-centred training models and interventions.  | <ul style="list-style-type: none"> <li>• Case note audit</li> </ul>  | NICE (2012) Epilepsies: diagnosis and management (CG137) |
| 52   | Decision making | The AED treatment strategy should be individualised according to the seizure type, epilepsy syndrome, co-medication and co-morbidity, the child or young person lifestyle, and the preferences of the person and their family and/or carers as appropriate                      | <ul style="list-style-type: none"> <li>• Case note audit</li> </ul>  | NICE (2012) Epilepsies: diagnosis and management (CG137) |

|    | Area of care    | Standard   | Measurement Criteria/<br>Demonstration of<br>Compliance                          | Source   |
|----|-----------------|--|--|--|
| 53 | Decision making | In girls of childbearing potential, including young girls who are likely to need treatment into their childbearing years, the possibility of interaction with oral contraceptives should be discussed with the child and/or her carer, and an assessment made as to the risks and benefits of treatment with individual drugs. | <ul style="list-style-type: none"> <li>Case note audit</li> </ul>                | NICE (2012) Epilepsies: diagnosis and management (CG137) |
| 54 | Decision-making | Units should have written material available and the expertise to explain and discuss all relevant individual risks associated with epilepsy care  | <ul style="list-style-type: none"> <li>Evidence of local arrangements</li> </ul> | Epilepsy12 audit (2014 round 2 report)                   |
| 55 | Decision making | Decisions about medication and lifestyle issues should draw on both the expertise of the healthcare professional and the experiences, beliefs and wishes of the young person with epilepsy as well as their family and/or carers.  | <ul style="list-style-type: none"> <li>Case note audit</li> </ul>                | NICE (2012) Epilepsies: diagnosis and management (CG137) |
| 56 | Decision-making | Annual review should include an enquiry about side effects and a discussion of the treatment plan to ensure concordance and adherence to medication.   | <ul style="list-style-type: none"> <li>Case note audit</li> </ul>                | NICE (2012) Epilepsies: diagnosis and management (CG137) |
| 57 | Holistic care   | The physical, psychological and social needs of young people with epilepsy should always be considered by healthcare professionals. Attention should be paid to their relationships with family and friends, and at school.  | <ul style="list-style-type: none"> <li>Patient feedback</li> </ul>               | NICE (2012) Epilepsies: diagnosis and management (CG137) |
| 58 | Holistic care   | Involve children, young people, parents and carers in the design of services and the review of information resources   | <ul style="list-style-type: none"> <li>Evidence of local arrangements</li> </ul> | Epilepsy12 audit (2014 round 2 report)                   |
| 59 | Holistic care   | Review the information provided from a child and young person's point of view and take steps to make it easier to understand   | <ul style="list-style-type: none"> <li>Evidence of local arrangements</li> </ul> | Epilepsy12 audit (2014 round 2 report)                   |

|    | Area of care  | Standard  | Measurement Criteria/<br>Demonstration of<br>Compliance                          | Source   |
|----|---------------|---|--|--|
| 60 | Holistic care | Consider the activities available in waiting areas from a child and young person's point of view and ensure that there are suitable age-appropriate activities.   | <ul style="list-style-type: none"> <li>Evidence of local arrangements</li> </ul> | Epilepsy12 audit (2014 round 2 report)                     |
| 61 | Holistic care | Review processes for ensuring that patients are kept informed about appointments  | <ul style="list-style-type: none"> <li>Evidence of local arrangements</li> </ul> | Epilepsy12 audit (2014 round 2 report)                     |
| 62 | Holistic care | Educational, behavioural and emotional problems should be assessed as these issues can have a huge impact on children, young people and their families  | <ul style="list-style-type: none"> <li>Case note audit</li> </ul>                | Epilepsy12 audit (2014 round 2 report)                     |
| 63 | Holistic care | Children and young people should be supported throughout their education, recognising the impact that epilepsy has on learning, behaviour, mental health and wellbeing.   | <ul style="list-style-type: none"> <li>Case note audit</li> </ul>                | Healthy London Partnership<br>- Epilepsy guide for schools |
| 64 | Holistic care | Prompt identification of learning and behaviour needs in children with epilepsy is vital.   | <ul style="list-style-type: none"> <li>Evidence of local arrangements</li> </ul> | Healthy London Partnership<br>- Epilepsy guide for schools |
| 65 | Holistic care | Each school should have an up-to-date medical conditions policy.  | <ul style="list-style-type: none"> <li>Evidence of local arrangements</li> </ul> | Healthy London Partnership<br>- Epilepsy guide for schools |
| 66 | Holistic care | Children and young people with epilepsy should have appropriate supervision depending on their individual needs.  | <ul style="list-style-type: none"> <li>Evidence of local arrangements</li> </ul> | Healthy London Partnership<br>- Epilepsy guide for schools |
| 67 | Holistic care | Children under 5 years need consideration of extra support at school. This may need an education health care plan to support and may need funding. Primary school aged children and young people (6 years+) require support to manage their epilepsy in school in line with the Children and Families Act 2014. In secondary school, students will be largely independent but may require intermittent support. | <ul style="list-style-type: none"> <li>Evidence of local arrangements</li> </ul> | Healthy London Partnership<br>- Epilepsy guide for schools |

|                            | Area of care | Standard  | Measurement Criteria/<br>Demonstration of<br>Compliance   | Source   |
|----------------------------|--------------|---|---|--|
| <b>SUPPORT/INFORMATION</b> |              |   |   |  |
|                            |              | <p><b>12) CYP with epilepsy should have access to a trained epilepsy specialist nurse advice within 24 hours or, if out-of-hours, on the next working day</b></p> <p><b>13) Every CYP with epilepsy should be offered appropriate mental health, behavioural and cognitive assessment, by an appropriately trained professional, independent of seizure activity</b></p> <p><b>14) CYP with epilepsy should be signposted to available self-management and peer support opportunities wherever possible.</b></p> <p><b>15) Shared decision-making within consultations, and methods to ensure CYPF influence on services, should be encouraged and promoted</b></p> |   |  |
| 68                         | Information  | Children and young people with epilepsy and their families and/or carers should be given, and have access to sources of, information including: their epilepsy and its prognosis, safety advice, medication, what to do in an emergency, SUDEP, the wider impact of epilepsy (e.g. psychological, learning), lifestyle issues   | <ul style="list-style-type: none"> <li>Evidence of local arrangements</li> <li>Case note audit</li> </ul> | NICE (2012) Epilepsies: diagnosis and management (CG137) |
| 69                         | Information  | Children and young people with epilepsy should be given information about their seizure type(s) and epilepsy syndrome, and the likely prognosis.  | <ul style="list-style-type: none"> <li>Case note audit</li> </ul>   | NICE (2012) Epilepsies: diagnosis and management (CG137) |
| 70                         | Information  | Information should be provided to children and young people and families and/or carers as appropriate about the reasons for considering surgery. The benefits and risks of the surgical procedure under consideration should be fully explained before informed consent is obtained.  | <ul style="list-style-type: none"> <li>Case note audit</li> </ul>   | NICE (2012) Epilepsies: diagnosis and management (CG137) |

|    | Area of care | Standard   | Measurement Criteria/<br>Demonstration of<br>Compliance                          | Source   |
|----|--------------|--|--|--|
| 71 | Information  | When prescribing sodium valproate to women and girls of present and future childbearing potential, discuss the possible risk of malformation and neurodevelopmental impairments in an unborn child, particularly with high doses of this AED or when using as part of polytherapy. | <ul style="list-style-type: none"> <li>Case note audit</li> </ul>                | NICE (2012) Epilepsies: diagnosis and management (CG137) |
| 72 | Information  | In order to enable informed decisions and choice, and to reduce misunderstandings, women and girls with epilepsy and their partners, as appropriate, must be given accurate information and counselling about contraception, conception and pregnancy.                             | <ul style="list-style-type: none"> <li>Case note audit</li> </ul>                | NICE (2012) Epilepsies: diagnosis and management (CG137) |
| 73 | Information  | Women and girls with epilepsy need accurate information during pregnancy, and the possibility of status epilepticus and SUDEP should be discussed with all women and girls who plan to stop AED therapy.   | <ul style="list-style-type: none"> <li>Case note audit</li> </ul>                | NICE (2012) Epilepsies: diagnosis and management (CG137) |
| 74 | Support      | Children and young people with epilepsy should have an accessible point of contact with specialist services. This should include access to a trained epilepsy specialist nurse advice within 24 hours or, if out-of-hours, on the next working day.                                | <ul style="list-style-type: none"> <li>Evidence of local arrangements</li> </ul> | NICE (2012) Epilepsies: diagnosis and management (CG137) |
| 75 | Support      | Children, young people and families should be signposted to third sector/voluntary sector organisations, including written literature and websites.  | <ul style="list-style-type: none"> <li>Case note audit</li> </ul>                | Young Epilepsy, Epilepsy Action, Epilepsy Society        |
| 76 | Support      | An interpreter should have both cultural and medical awareness. Interpreters from the family are generally not suitable because of issues around confidentiality, privacy, personal dignity, and accuracy.   | <ul style="list-style-type: none"> <li>Evidence of local arrangements</li> </ul> | NICE (2012) Epilepsies: diagnosis and management (CG137) |

|  | Area of care | Standard  | Measurement Criteria/<br>Demonstration of<br>Compliance   | Source   |
|--|--------------|---|---|--|
| <b>WORKFORCE, EDUCATION AND TRAINING</b> |              |   |   |  |
| 77                                       | Workforce    | All services working with children and young people with epilepsy should have at least one expert epilepsy paediatrician in their unit. If needed, processes should be changed to ensure that children and young people get better access to these specialists  | <ul style="list-style-type: none"> <li>Evidence of appropriate, up-to-date qualifications (PET course trained, plus CPD)</li> </ul> | Epilepsy12 audit (2014 round 2 report)<br>PET course (Paediatric Epilepsy Training)  |
| 78                                       | Workforce    | Epilepsy specialist nurses (ESNs) should be an integral part of the network of care of children and young people with epilepsy. The key roles of the ESNs are to support both epilepsy specialists and generalists, to ensure access to community and multi-agency services and to provide information, training and support to the child, young person, families, carers and, in the case of children, others involved in the child's education, welfare and well-being. | <ul style="list-style-type: none"> <li>Evidence of access to ESN</li> </ul>   | NICE (2012) Epilepsies: diagnosis and management (CG137)<br>RCN 2013 Specialist nursing of children and young people with epilepsy |
| 79                                       | Workforce    | Units that have an epilepsy specialist nurse, but where many children and young people with epilepsy are still not having input from them, should improve their care pathways and referral strategies to ensure that this input is always available   | <ul style="list-style-type: none"> <li>Evidence of access to ESN</li> </ul>   | Epilepsy12 audit (2014 round 2 report)   |
| 80                                       | Workforce    | The tertiary service should include a multidisciplinary team, experienced in the assessment of children and young people with complex epilepsy, and have adequate access to investigations and treatment by both medical and surgical means.  | <ul style="list-style-type: none"> <li>Evidence of local staffing/access arrangements</li> </ul>                                    | NICE (2012) Epilepsies: diagnosis and management (CG137)   |

|    | Area of care | Standard   | Measurement Criteria/<br>Demonstration of<br>Compliance   | Source   |
|----|--------------|--|---|--|
| 81 | Workforce    | The expertise of multidisciplinary teams involved in managing complex epilepsy should include psychology, psychiatry, social work, occupational therapy, counselling, neuroradiology, clinical nurse specialists, neurophysiology, neurology, neurosurgery and neuroanaesthesia. Teams should have MRI and video telemetry facilities available to them. | <ul style="list-style-type: none"> <li>Evidence of local staffing/access arrangements</li> </ul>  | NICE (2012) Epilepsies: diagnosis and management (CG137) |
| 82 | Workforce    | The neurosurgeon in the multidisciplinary team should have specialist experience of and/or training in epilepsy surgery and have access to invasive EEG recording facilities.  | <ul style="list-style-type: none"> <li>Evidence of appropriate, up-to-date CPD</li> <li>Evidence of local staffing/access arrangements</li> </ul> | NICE (2012) Epilepsies: diagnosis and management (CG137) |
| 83 | Training     | Healthcare professionals have a responsibility to educate others about epilepsy so as to reduce the stigma associated with it. They should provide information about epilepsy to all people who come into contact with children and young people with epilepsy, including school staff, social care professionals and others.                            | <ul style="list-style-type: none"> <li>Evidence of local staffing/access arrangements</li> </ul>  | NICE (2012) Epilepsies: diagnosis and management (CG137) |
| 84 | Training     | All healthcare professionals who treat, care for, or support women and girls with epilepsy should be familiar with relevant information and the availability of counselling.   | <ul style="list-style-type: none"> <li>Evidence of appropriate, up-to-date CPD.</li> </ul>  | NICE (2012) Epilepsies: diagnosis and management (CG137) |
| 85 | Training     | Healthcare professionals should adopt a consulting style that allows the young person with epilepsy to participate as a partner in the consultation.   | <ul style="list-style-type: none"> <li>Patient feedback</li> </ul>  | NICE (2012) Epilepsies: diagnosis and management (CG137) |

|                              | Area of care   | Standard  | Measurement Criteria/<br>Demonstration of<br>Compliance           | Source  |
|------------------------------|----------------|---|---|---|
| <b>PREGNANCY</b>             |                |   |   |   |
| 86                           | Pregnancy      | Sodium valproate should not be prescribed to girls or women who are pregnant, or who may become pregnant in the future, unless other anti-epileptic drugs (AEDs) do not work to control seizures, or they cause unbearable side effects.  | <ul style="list-style-type: none"> <li>Case note audit</li> </ul> | Epilepsy Society 2016 MHRA (Medicines and Healthcare Products Regulatory Agency) guidelines |
| 87                           | Pregnancy      | Women and girls taking sodium valproate need to use an effective method of contraception to avoid an unplanned pregnancy. As some anti-epileptic drugs can affect how well some contraceptive methods work, it is important to use the most effective methods for your situation, and ask your specialist or family planning advisor for advice if necessary.   | <ul style="list-style-type: none"> <li>Case note audit</li> </ul> | Epilepsy Society 2016 MHRA (Medicines and Healthcare Products Regulatory Agency) guidelines |
| 88                           | Pregnancy      | Women and girls with epilepsy need to talk to their specialist about their drug treatment: <ul style="list-style-type: none"> <li>- before they become pregnant and before they stop taking their contraception, or</li> <li>- as soon as possible if they are already pregnant.</li> </ul> This preconception counselling is essential when taking any anti-epileptic drugs, but especially so for sodium valproate. | <ul style="list-style-type: none"> <li>Case note audit</li> </ul> | Epilepsy Society 2016 MHRA (Medicines and Healthcare Products Regulatory Agency) guidelines |
| <b>LEARNING DISABILITIES</b> |                |   |   |   |
| 89                           | Diagnosis      | Diagnosis may be difficult, so care should be taken to obtain a thorough history, ideally with an eye witness account and/or video.   | <ul style="list-style-type: none"> <li>Case note audit</li> </ul> | NICE (2012) Epilepsies: diagnosis and management (CG137)                                    |
| 90                           | Investigations | Those with learning disabilities may require particular care and attention to tolerate investigations.  | <ul style="list-style-type: none"> <li>Case note audit</li> </ul> | NICE (2012) Epilepsies: diagnosis and management (CG137)                                    |

|    | Area of care   | Standard  | Measurement Criteria/<br>Demonstration of<br>Compliance   | Source   |
|----|----------------|---|---|--|
| 91 | Investigations | Facilities, or pathway, should be available for imaging under anaesthesia, if necessary.  | <ul style="list-style-type: none"> <li>Evidence of regional arrangements/referral pathway</li> <li>Case note audit</li> </ul> | NICE (2012) Epilepsies: diagnosis and management (CG137) |
| 92 | Investigations | In the child or young person presenting with epilepsy and learning disability, investigations directed at determining an underlying cause should be undertaken.   | <ul style="list-style-type: none"> <li>Case note audit</li> </ul>   | NICE (2012) Epilepsies: diagnosis and management (CG137) |
| 93 | Holistic care  | Do not discriminate against children or young people with learning disabilities, and offer the same services, investigations and therapies as for the general population.   | <ul style="list-style-type: none"> <li>Patient feedback</li> </ul>  | NICE (2012) Epilepsies: diagnosis and management (CG137) |
| 94 | Holistic care  | Ensure adequate time for consultation to achieve effective management of epilepsy in children and young people with learning disabilities.  | <ul style="list-style-type: none"> <li>Evidence of local arrangements</li> </ul>  | NICE (2012) Epilepsies: diagnosis and management (CG137) |
| 95 | Care planning  | Enable children and young people who have learning disabilities, and their family and/or carers, to take an active part in developing a personalised care plan for treating their epilepsy while taking into account any comorbidities. | <ul style="list-style-type: none"> <li>Evidence of local arrangements</li> </ul>  | NICE (2012) Epilepsies: diagnosis and management (CG137) |
| 96 | Care planning  | In making a care plan for a child or young person with learning disabilities and epilepsy, particular attention should be paid to the possibility of adverse cognitive and behavioural effects of AED therapy.                          | <ul style="list-style-type: none"> <li>Case note audit</li> </ul>   | NICE (2012) Epilepsies: diagnosis and management (CG137) |

|                   | Area of care   | Standard  | Measurement Criteria/<br>Demonstration of<br>Compliance                                     | Source   |
|-------------------|--|---|---|--|
| 97                | Education  | Healthcare professionals should be aware of the higher risks of mortality for children and young people with learning disabilities and epilepsy and discuss these with them, their families and/or carers.  | <ul style="list-style-type: none"> <li>Evidence of appropriate, up-to-date CPD</li> </ul>   | NICE (2012) Epilepsies: diagnosis and management (CG137)   |
| <b>TRANSITION</b> |  |   |   |  |
|                   | <b>16) CYP with epilepsy should have access to structured transition planning towards adult services, as early as possible</b> |   |   |  |
| 98                | Transition   | Starting to plan transition for young people moving from children's to adults' services as early as possible can lead to a better experience, & allows young people more time to be involved in decisions & to adjust to changes to their future care. (Conversely, a sudden move to adults' services with no time for preparation or support can lead to young people and their families losing confidence & disengaging with services). | <ul style="list-style-type: none"> <li>Evidence of locally agreed policy/pathway</li> </ul> | NICE Quality standard [QS140] Transition from children's to adults' services (2016)<br><a href="https://www.nice.org.uk/guidance/qs140/resources/transition-from-childrens-to-adults-services-pdf-75545472790213">https://www.nice.org.uk/guidance/qs140/resources/transition-from-childrens-to-adults-services-pdf-75545472790213</a><br><br>HLP acute care standards |
| 99                | Transition   | A named clinician should assume responsibility for the ongoing management of the young person with epilepsy and ensure smooth transition of care to adult services, and be aware of the need for continuing multi-agency support.   | <ul style="list-style-type: none"> <li>Evidence of locally agreed policy/pathway</li> </ul> | NICE (2012) Epilepsies: diagnosis and management (CG137)   |
| 100               | Transition   | Multidisciplinary services provided jointly by adult and paediatric specialists have a key role in the care of the young person with epilepsy. This can facilitate the transition from paediatric to adult services and aid in the dissemination of information.  | <ul style="list-style-type: none"> <li>Evidence of locally agreed policy/pathway</li> </ul> | NICE (2012) Epilepsies: diagnosis and management (CG137)   |

|   | Area of care | Standard  | Measurement Criteria/<br>Demonstration of<br>Compliance  | Source   |
|---|--------------|---|--|--|
| 101                                       | Transition   | The information given to young people should cover epilepsy in general and its diagnosis and treatment, the impact of seizures and adequate seizure control, treatment options including side effects and risks, and the risks of injury. Other important issues to be covered are the possible consequences of epilepsy on lifestyle and future career opportunities and decisions, driving and insurance issues, social security and welfare benefit issues, sudden death and the importance of adherence to medication regimes. Information on lifestyle issues should cover recreational drugs, alcohol, sexual activity and sleep deprivation. | <ul style="list-style-type: none"> <li>Case note audit</li> </ul>  | NICE (2012) Epilepsies: diagnosis and management (CG137)   |
| <b>SERVICE PLANNING AND COMMISSIONING</b> |              |   |  |  |
| 102                                       | Audit        | Units should now review their local results and identify aspects of patient care and services that need to be improved. Units should also take part in National Clinical Audit (Epilepsy12).  | <ul style="list-style-type: none"> <li>Evidence of local audit</li> <li>Participation in Epilepsy12</li> </ul>                             | Epilepsy12 audit (2014 round 2 report)   |
| 103                                       | Audit        | Units should develop action plans outlining how they intend to improve local patient care and make a case to hospital managers and commissioners for additional resources   | <ul style="list-style-type: none"> <li>Evidence of local audit</li> <li>Participation in Epilepsy12, with resulting action plan</li> </ul> | Epilepsy12 audit (2014 round 2 report)   |
| 104                                       | Workforce    | Funders/commissioners of services must ensure that there are sufficient, appropriately qualified epilepsy specialist nurses, and of clinicians with an expertise in epilepsy, in order to provide good standards of care for children/young people and their families.  | <ul style="list-style-type: none"> <li>Evidence of local arrangements</li> </ul>   | RCN 2013 Specialist nursing of children and young people with epilepsy<br>NICE (2012) Epilepsies: diagnosis and management (CG137) |

|     | <b>Area of care</b> | <b>Standard</b>   | <b>Measurement Criteria/<br/>Demonstration of<br/>Compliance</b>           | <b>Source</b>  |
|-----|---------------------|---|--|--|
| 105 | Standards           | Units should offer care that complies with established service standards (such as this document), and meets the Best Practice Tariff (BPT) criteria | <ul style="list-style-type: none"><li>Evidence of BPT compliance</li></ul> | NHS England Best Practice Tariff (TFC 223) Paediatric Epilepsy |

# Appendices

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## Acknowledgements

Dr Amit Bali, Clinical Leadership Fellow, Young Epilepsy; Consultant Paediatrician, Lewisham and Greenwich NHS Trust; Honorary Research Associate, Population, Policy and Practice, University College London, Institute of Child Health

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Dr Christin Eltze, Consultant Paediatric Neurologist, Great Ormond Street Hospital for Children NHS Foundation Trust, London

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Dr Eugenia Lee, GP, Primary care clinical advisor, Healthy London Partnership

Carol Long, Chief Executive, Young Epilepsy

Sara Nelson Programme Lead Healthy London Partnership, Children and young people's programme, Queens Nurse

Dr Christina Petropoulos, Consultant Paediatrician University College London Hospital and Royal College of Paediatric and Child Health College Tutor

Dr Kerry Robinson, Consultant Paediatrician, Whittington Health, London

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## APLS algorithm for management of status epilepticus

(Source: NICE guidance (2012))

|                                   |   |   |
|-----------------------------------|---|---|
| <b>Time</b>                       | Seizure starts  | Confirm clinically that it is an epileptic seizure  |
| 0 mins<br>(1 <sup>st</sup> step)  | Check ABC, high flow O <sub>2</sub> if available<br><br>Check blood glucose<br><br>Consider blood electrolytes and calcium at this point        |   |
| 5 mins<br>(2 <sup>nd</sup> step)  | Midazolam 0.5 mg/kg buccally or<br><br>Lorazepam 0.1 mg/kg if intravenous access established  | Midazolam may be given by parents, carers or ambulance crew in non-hospital setting. Note that ambulance crew typically use rectal diazepam   |
| 15 mins<br>(3 <sup>rd</sup> step) | Lorazepam 0.1 mg/kg intravenously   | This step should be in hospital<br><br>Call for senior help<br><br>Start to prepare phenytoin for 4 <sup>th</sup> step<br><br>Re-confirm it is an epileptic seizure                                       |
| 25 mins<br>(4 <sup>th</sup> step) | Phenytoin 20 mg/kg by intravenous infusion over 20 mins<br><br>or (if on regular phenytoin)<br>Phenobarbital 20 mg/kg intravenously over 5 mins | Paraldehyde 0.8 ml/kg of mixture may be given after start of phenytoin infusion as directed by senior staff or whilst making up the infusion<br><br>Inform intensive care unit and/or senior anaesthetist |
| 45 mins<br>(5 <sup>th</sup> step) | Rapid sequence induction of anaesthesia using thiopental sodium 4 mg/kg intravenously   | Transfer to paediatric intensive care unit  |

### Additional guidance

As well as checking glucose it is helpful to take blood for electrolytes, calcium and magnesium and also take blood cultures if the child is febrile. If the blood glucose is less than 3mmols/L,

appropriate 'hypoglycaemia screen' blood tests should be taken immediately, followed by treatment of the hypoglycaemia with 2mls/kg intravenous 10% dextrose, followed by prescribing an infusion.

**It is important to give enough time for the drugs to work to avoid respiratory depression from benzodiazepine overdose.**

If the child is febrile, then antipyretics can be given (such as Paracetamol intravenously or rectally).

If the cause of the seizure is uncertain, and a diagnosis of meningoencephalitis is a possibility, prescribe ceftriaxone, aciclovir and clarithromycin. IV aciclovir should be seriously considered for focal seizures of unknown cause. Local antimicrobial pathways should be followed.

If there are signs of raised intracranial pressure, mannitol 250mg/kg over 30-60minutes or 2.7% Sodium Chloride 3mL/kg over 10-20mins can be given through a central line ideally. The aim is for NaCl of 145mmol.

**A lumbar puncture should not be performed if there is a reduced level of consciousness or focal onset seizures until there has been a discussion with a senior paediatrician.**

Consider a CT scan +/- contrast if seizures are atypical /focal or the diagnosis is uncertain. It is likely that the patient will need to be stabilised together with the anaesthetist ahead of this. A portable ventilator will be needed if the child is ventilated with end tidal CO2 monitoring in place.

Indications for ventilation include if the child is in convulsive status epilepticus 20 minutes after starting IV phenytoin/phenobarbitone, or if the airway is compromised at any time.

## References

### Introduction

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