Written evidence submitted by Epilepsy Action (DEL0156)

About Epilepsy Action

Epilepsy Action is the UK’s leading epilepsy organisation and exists to improve the lives of everyone affected by the condition. As a member-led organisation, we are led by and represent people with epilepsy, their friends, families and healthcare professionals. Epilepsy can affect anyone at any age and from any walk of life.

Epilepsy is one of the most common serious neurological conditions in the world. It affects around 600,000 people in the UK. This means that 1 in 100 people in the UK have epilepsy. Around 87 people are diagnosed with epilepsy in the UK every day. The condition is unpredictable and fluctuating, meaning it affects people in different ways and its impact can vary from day to day.

Summary of key points

1. The well-established and potentially severe risks associated with epilepsy call for an urgent and comprehensive response in the immediate, mid and longer term to protect and support people living with the condition

2. NHS Trusts should ensure that key epilepsy services are maintained during the COVID-19 pandemic to prevent risk and minimise premature epilepsy related mortality

3. Triaging and specialist support should be maintained for most at risk epilepsy patients, including suspected first seizures and those with complex epilepsies.

4. Epilepsy specialist nurses (ESNs) and other key epilepsy healthcare professionals (HCPs) should be prioritised for redeployment to epilepsy services as soon as safely possible

5. Key epilepsy health services that have been reduced or put on hold due to the COVID-19 pandemic should be prioritised for resumption when service capacity allows

Submission response

Given the well-established and potentially severe risks associated with the condition, epilepsy health services require more focus and attention at a system level than has currently been afforded during the COVID-19 pandemic.

The submission response is structured around three main sections:

1.) Impact of the COVID-19 pandemic on the provision of epilepsy health services
2.) Optimising care for people with epilepsy during the COVID-19 pandemic.
3.) Redeployment of healthcare professionals and resumption of wider epilepsy services
Specific focus is also given to the most at risk patient groups and actions that should be taken to mitigate potential increased risks to patients and prevent premature epilepsy related mortality during and after the COVID-19 pandemic.

**Impact of the COVID-19 pandemic on the provision of epilepsy health services**

- Some people with suspected first seizures are experiencing delays to accurate diagnosis and subsequent treatment plans (medication) in light of skeleton epilepsy services in some hospitals and Trusts. While teleclinics are suitable for many existing epilepsy patients, diagnosis, and in particular more complex diagnoses, can be challenging through teleclinics, as highlighted in discussions with neurologists.

- Epilepsy Action is aware of reduced capacity for and availability of diagnostic testing, including EEGs, which are sometimes needed to assist in accurate epilepsy diagnoses.

- This presents a potentially increased to people with suspected first seizures in the short term and potential for a longer term backlog of patients requiring these services – and further subsequent delays to accurate diagnosis - when they are more widely available. More generally, there are a number of other interventions that cannot be delivered through teleclinics or during periods of reduced service provision including VNS adjustments and changes to medications with associated increased risk.

- Redeployment of epilepsy specialist nurses (ESNs) to general medicine and COVID-19 wards, combined with staff sickness, is causing challenges for some people with epilepsy.

- Epilepsy specialist nurses are often the first point of contact for people with epilepsy who require advice or support related to their condition. Some hospitals and Trusts currently have no ESN contact for people with epilepsy with answerphone messages stating that services are not available at present, leading to potential increased risk.

- While some regions are continuing to provide a reduced ESN telephone services or SOS services, these are suboptimal and could present a potential increased risk to people with epilepsy. The crucial role of epilepsy specialist nurses in caring for and supporting people with epilepsy is set out in Epilepsy Action’s recent ESPENTE report ([https://www.epilepsy.org.uk/research/espente](https://www.epilepsy.org.uk/research/espente))

- People with epilepsy face an increased risk of mental health conditions, including anxiety and depression. These are likely to be exacerbated by prolonged periods of social distancing and self-isolation especially when combined with a lack of access to ESN support (as set out above).

- Stress and anxiety can be a seizure trigger for some people with epilepsy potentially contributing to worsening seizure control. Consideration should be given to a potential prioritisation in accessing mental health services for people at increased risk of mental health challenges when these services begin to resume.
• Some neurologists have reported concerns around people with epilepsy who have been contacted to attend emergency clinics taking the decision not to attend appointments in light of concerns about the virus and strong government messaging around staying at home and protecting the NHS.

• Feedback from patients has been that they would rather wait until normal service begins to resume. There are also anecdotal concerns about reducing numbers of people presenting at GPs or A&E with suspected first seizures.

• People not entering care pathways or attending emergency clinics present potentially significant risks to individuals in the short to medium term. There are also associated service level risks relating to capacity issues when normal services begin to resume. Potential influx of suspected first seizure patients and existing epilepsy patients with deterioration in seizure control or similar could overwhelm services.

Optimising care for people with epilepsy during the COVID-19 pandemic

Epilepsy Action is in the process of consulting with relevant clinicians and other key stakeholders to reach consensus on how best to optimise care in order to prevent epilepsy related harms and premature epilepsy related mortality during the COVID-19 pandemic.

Two patient groups have been identified as particularly relevant to achieving this aim:
  o People with suspected first seizures
  o Existing epilepsy patients identified as at most risk.

Any discussion of care optimisation in the context of the COVID-19 pandemic is not intended to inform normal service provision, which provides more optimal care. Full epilepsy service provision should be resumed as a matter of urgency when resource capacity allows.

The recommendations set out below are intended as a minimum floor for provision of some epilepsy services during the pandemic. Epilepsy Action is aware that epilepsy service provision during COVID-19 in some areas exceed these recommendations. Alternative methods of service provision that differ from our recommendations, while focussing on preventing harm and premature morality, are also being utilised in some areas.

Provision of increased or alternate epilepsy services is, of course, welcome. The recommendations are specifically applicable to areas that are currently running services below those set out in the recommendations, or not running particular services at all.

Associated work to make the case for epilepsy services to be prioritised for redeployment of HCPs and resumption of normal services where and when appropriate is being planned.


**Recommendations for optimising care for people with epilepsy during COVID-19 pandemic**
1. **People with suspected first seizures are able to access to diagnostic services even if some tests not available**

**Key patient group:** suspected first seizure.

For people presenting with first seizures, access to a diagnosis process is crucial. Without a confirmed epilepsy diagnosis, patients are unable to access medication or other treatments presenting an increased risk.

It is recognised that face-to-face appointments will not be possible or desirable in all cases and that access to some diagnostic tests will be limited or unavailable.

The focus of services should be on providing a limited diagnosis process to reduce risks to the person and to prevent a backlog of people with suspected epilepsy overwhelming the system when normal services begin to resume.

A basic first seizure service should involve video/teleclinics, capacity for improved video sharing to aid accurate diagnosis and clearly defined processes for referrals to urgent diagnostic testing or other inpatient services.

Ensuring that a treatment plan can be agreed and prescriptions can be issued could reduce the immediate risk faced by this patient group. This is not the normal or optimum process for diagnosis or making treatment decisions but could be a preferable option to no treatment plan or medication with ongoing active seizures and associated risks. These patients should be prioritised for face-to-face appointments where necessary when normal service resume.

2. **Services proactively triage existing patients where possible and offer telephone reviews for those at most risk to prevent deterioration and admission**

**Key patient group:** existing epilepsy patients (most at risk)

Regional epilepsy services should use existing mechanisms, ideally coding, to identify people with epilepsy who are at most risk in normal circumstances and additionally those who are at a potentially increased risk during the COVID-19 pandemic. Parameters for this will vary on a case-by-case basis but as a minimum should include the patient groups listed below.

Most at risk patients include: those with comorbidities, severe/ treatment-resistant epilepsies, transition, homeless, prison populations and pregnant women (non-exhaustive list).

Those identified at a system level as being in the most at-risk group should be prioritised for video/teleclinic appointments and other necessary interventions. Judgements would also have to be made to prioritise within the most at-risk groups in the event of severely reduced epilepsy services at a hospital, Trust or regional level. This could involve grouping patients according to those who (1) need to be seen through video/teleclinic as soon as possible (2) need to be seen soon but not immediately or (3) have no need to be seen soon and can be delayed.
Identifying at risk patients in the absence of adequate coding is likely to be challenging. In an attempt to mitigate this, identification of at-risk patients should happen through 1.) Service level identification set out above (coding or existing staff knowledge) and 2.) Patient self-identification.

For patient self-identification as high risk, parameters should be clearly defined and communicated out to patient populations. Focus here is on existing higher risk epilepsy patients who would not get picked up through service level ID and those who would not generally constitute high risk but become so due to unforeseen factors or as a consequence of reduced service provision in the current context.

This would include people with epilepsy who are experiencing worsening seizure control (relative to normal seizure control); people experiencing an increased severity of seizures (relative to normal seizures); and those who are experiencing severe side effects from anti-seizure medications or problems with VNS.

Routes for patients to contact and self-ID as high risk need to be established – potentially utilising reduced point of contact as per service 3 below – and shared with patients.

3. People with epilepsy are able to contact neurology services if they have problems and a plan to respond is in place.

Key patient group: existing epilepsy patients (general)

The redeployment of epilepsy specialist nurses (ESNs) to coronavirus related roles has led to a significant gap in patient access to vital specialist nurse support in some areas.

Where possible, services should look to maintain at least one existing epilepsy specialist nurse (ESN) contact method, staffed for at least part of the day.

Alternatively, services should look to introduce an SOS contact line to ensure that people with epilepsy who are unable to access ESN support can contact a relevant service and where necessary, be supported or triaged accordingly.

Redeployment of healthcare professionals and resumption of wider epilepsy services

- Moving forward, Epilepsy Action believes there is a strong case for epilepsy services to be prioritised for redeployment of healthcare professionals and the resumption of key services when system capacity allows.

- Epilepsy presents a number of well-established risks to people with the condition that require a suite of health services to prevent harms and minimise premature epilepsy related mortality.

- Risks associated with the condition include risk of injury and premature epilepsy related mortality, including status epilepticus & sudden unexpected death in epilepsy (SUDEP).
Comorbidities are more prevalent in the epilepsy population than in the general population, including both physical and mental health comorbidities. Additional risks are associated with these patient groups.

The impact of a prolonged period of significantly reduced epilepsy service provision could be severe and the likely increase in urgent cases requiring inpatient services when capacity allows and patient confidence returns could present ongoing capacity challenges for epilepsy services and associated risks to people with the condition.

Services can help to mitigate these risks by ensuring that care is optimised during the immediate pandemic, as set out in the previous section.

An expanded suite of key services should be bought back online as a matter of urgency and services should use coding wherever possible and other methods to appropriately triage and prioritise patients.

New ways of working and alternate methods of service provision that have been shown to be effective for people with epilepsy and clinicians during this time – including telemedicine for some appointments and improved video sharing in the diagnosis pathway – should be considered and consulted on with a view to embedding the most effective when normal services resume.

It is important to acknowledge that for some patients, including vulnerable patient groups and those with complex epilepsies, telemedicine may not be possible or appropriate and plans must be put in place to provide face-to-face care wherever necessary.

It is vital that embedding new ways of working or alternate methods of service provision does not exacerbate existing health inequalities. Public Health England have previously highlighted the significant relationship between deprivation and epilepsy-related mortality. (https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/683860/Deaths_associated_with_neurological_conditions_data_analysis_report.pdf)

Key epilepsy health services that should be brought back online as soon as possible where they have been reduced or suspended in specific regions, NHS Trusts and hospitals include, but are not limited to:

- Redeployment of epilepsy specialist nurses (ESNs)
- Resumption of diagnostic testing
- Resumption of first seizure clinics
- Resumption of inpatient services for complex epilepsies
- Resumption of planned epilepsy surgery
- Resumption of VNS adjustments
- Resumption of mental health support for people with neurological conditions, including
• Moving forward Epilepsy Action believes there is a strong case to be made for full epilepsy services to be resumed as soon as capacity allows. The information set out above demonstrates risks associated with epilepsy and steps that should be taken to mitigate such risks during the current COVID-19 pandemic and in the period immediately after.

• Ultimately the best way to prevent epilepsy related harms and premature epilepsy related mortality is for normal services to resume as a matter of urgency. Epilepsy Action will set out the case for this in detail in the coming weeks. We would be delighted to share this forthcoming work with the Committee.

• Prior to the COVID-19 pandemic there was a concerted system level effort to review and optimise epilepsy services utilising NHS RightCare and Getting It Right First Time (GIRFT) amongst other programmes and partners. It is vitally important that the national and local focus on improving epilepsy health services continues whenever and wherever it is possible to do so.

• Post-COVID, national and local health services should focus on addressing epilepsy related challenges and improving epilepsy health services with reference to, amongst others, NHS RightCares Epilepsy Toolkit, [https://www.england.nhs.uk/rightcare/wp-content/uploads/sites/40/2020/03/rightcare-epilepsy-toolkit-v2.pdf](https://www.england.nhs.uk/rightcare/wp-content/uploads/sites/40/2020/03/rightcare-epilepsy-toolkit-v2.pdf)

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