

## **Optimising healthcare for people with epilepsy during the COVID-19 pandemic (final draft for consultation) June 2020**

The NHS RightCare Epilepsy Toolkit, launched in January 2020 recognised that “People with epilepsy are at increased risk of dying suddenly and prematurely. Nearly half of these unexpected deaths are potentially avoidable, with improved access to information, services and better risk management.” During the COVID-19 pandemic there has been a necessary reorganisation of epilepsy service delivery. This Consensus statement sets out the expected service provision for children, young people and adults with epilepsy and first seizures during the COVID-19 pandemic; this is in keeping with recent publications.<sup>1 2</sup> Rapid service reorganisation must not produce undue risk for people with epilepsy and first seizures.

Given the pace of the COVID-19 pandemic, this statement is tightly time limited and will be regularly reviewed in line with the UK Government plan to rebuild<sup>3</sup> and on a rolling basis in light of emerging evidence of the impact of service optimisation measures during and beyond the COVID-19 pandemic. It should be superseded and discarded as soon as clinical capacity allows.

NHS RightCare Epilepsy Toolkit<sup>4</sup> and the delayed NHS England Neuroscience Transformation Programme Optimum Epilepsy Pathway set out what good looks like for epilepsy health services and should remain the backbone of epilepsy services. Full implementation of these resources is essential in time; despite the pandemic presenting challenges it has also been shown to speed up cross system working and innovation. First phase priorities for implementation of good practice to tackle SUDEP and all epilepsy-related mortality in the Toolkit include good practice consensus measures chosen for high impact and ease of implementation. Methods for care delivery to adapt to enable this would be needed.

### **1. People with suspected first seizures must have access to a consultation with a clinician with expertise in epilepsy and to appropriate diagnostic tests**

For children, young people and adults with suspected first seizures, access to clinical expertise is crucial to confirm a diagnosis, request relevant investigations, provide advice to minimise future risk (e.g. injury, driving, bathing, employment, death) and where necessary initiate antiepileptic drug treatment.

Face-to-face appointments may not be possible or desirable, and most appointments can be undertaken via telephone or video communication apps. If not already implemented, services should do so immediately to avoid a backlog of appointments, and unnecessary risk. Services will inevitably find any backlog difficult to tackle as we emerge from the pandemic. Prompt access to ECG, EEG and brain imaging needs to be negotiated at a local level.

### **2. People with epilepsy (PWE) and parents/carers should be able to contact neurology services if they have problems, and a plan to respond should be in place.**

In addition to accessing primary care it is vital that PWE, parents and carers are able to make contact with epilepsy services and ask for help, particularly if there is deterioration in their seizure control, mental health or behaviour. As a minimum they should have access to the telephone number of their consultant’s secretary and their epilepsy nurse specialist. These numbers should be available on hospital websites.

The redeployment of epilepsy specialist nurses (ESNs) to coronavirus related roles has led to a significant gap in patient access to vital support in some areas. It is essential that a clear pathway to access ESNs is in place, services should provide access to at least one existing epilepsy specialist nurse (ESN) contact method, staffed for at least six hours on a week day. Urgent calls and e-mails should be responded to within 2 working days this can prevent unnecessary hospital admissions and emergency department attendances.

### **3. Epilepsy clinical staff should be prioritised for repatriation to epilepsy services**

Epilepsy specialist consultants and nurses are best placed to support PWE and provide the immediate and ongoing care necessary to minimise future risk. Prioritising these staff for return to pre-COVID roles is essential for the optimal delivery of the two recommendations above. As services begin to return to normal provision, redeploying specialist staff at the earliest opportunity will ensure services are best positioned to meet potential increased demand. A Trust should be able to evidence on an ongoing basis why a full service has not been resumed. Service risk assessments should be documented, incident reports of any harms resulting from a reduced epilepsy service should be reviewed and acted upon to improve patient safety.

<sup>1</sup> <https://www.ncbi.nlm.nih.gov/pubmed/32354732>

<sup>2</sup> <https://n.neurology.org/content/early/2020/04/22/WNL.0000000000009632>

<sup>3</sup> <https://www.gov.uk/government/publications/our-plan-to-rebuild-the-uk-governments-covid-19-recovery-strategy/our-plan-to-rebuild-the-uk-governments-covid-19-recovery-strategy>

<sup>4</sup> <https://www.england.nhs.uk/rightcare/products/pathways/epilepsy-toolkit/>

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