

Commissioner's Guide to the NCEPOD Report - 'Disordered Activity'

A review of the quality of epilepsy care provided to adult patients presenting to hospital with a seizure

Introduction

Epilepsy is defined as the tendency to have recurrent seizures and is one of the most common long-term neurological conditions in the UK, affecting 0.8% of the population. Epilepsy is more commonly diagnosed in childhood or in older age, as well as in people who are socially deprived, have a learning disability, or in those who have had a stroke or brain injury. The condition can be life-threatening; deaths in pregnant women with epilepsy have doubled since 2016. People with epilepsy also have an increased risk of suicide and unintentional injury with sudden unexpected death in epilepsy (SUDEP) affecting 1.3 in 1000 patients per year and increasing annually by 3%. Despite national guidelines and standards on the care for patients with epilepsy, variation in care leads to delays in appropriate diagnosis, unnecessary readmissions and presentations to hospital, increased risk to the patient, as well as missed opportunities to review antiseizure medication prescriptions, educate patients about the condition and underline the importance of adherence to medication.

This NCEPOD study was developed with wide multidisciplinary input. It identifies a number of areas affecting the care and outcome of adult patients with epilepsy that require improvement. Particular focus was given to communication and co-ordination of care after emergency presentation with a seizure, neurology input in the emergency setting, the role of epilepsy specialist nurses and patient education regarding the risks associated with epilepsy.

Patient population

All patients aged 18 or over who presented to hospital following a seizure between 1st January 2020 and 31st December 2020 and who had a pre-existing epilepsy disorder or were subsequently diagnosed with epilepsy. Patients discharged from the emergency department and those admitted to hospital were included.

Up to six patients per hospital were selected for questionnaire completion and case note review. To avoid the effects of the COVID-19 pandemic on hospital admissions, these patients were selected from January and February 2020

Clinical issues

- 133/315 (42.2%) patients with epilepsy did not have their admission discussed with their usual secondary care team.
- 47/180 (26.1%) patients did not have their anti-seizure medication (ASM) written in their notes.
- 58/252 (23.0%) patients should have had additional investigations in the emergency department.
- 175/503 (34.8%) patients were reviewed by a neurologist during their admission and a further 109/503 (21.7%) had their epilepsy management discussed with a neurologist, leaving 219/503 (43.5%) patients without input.
- Only 36/494 (7.3%) patients were reviewed by an epilepsy specialist nurse.

- Case reviewers considered that neurology input was inadequate for 61/217 (28.1%) patients.
- Only 40/317 (12.6%) patients had any evidence in their notes that the risk of SUDEP had been considered and discussed with them.

Organisational issues

- At 45/143 (31.5%) hospitals reported that there was a policy for the emergency department to contact the epilepsy team when patients with known epilepsy were seen.
- 119/158 (75.3%) hospitals had the facility to perform an ASM blood screen on-site.
- Only 23/85 (27.1%) hospitals reported the waiting time for first seizure clinics to be within two-weeks following a first seizure.

Key features of a service

1. Communication between the treating team and the patient's 'usual' epilepsy treating team

Alert a patient's 'usual' epilepsy team, wherever based, when a patient presents with seizure.

This provides an opportunity to discuss the patient's needs and undertake an inpatient review if appropriate. To facilitate this, hospitals should have a system in place which enables emergency medicine/admitting clinicians to communicate with the patient's usual epilepsy clinical team. Use an existing electronic alert system if available or check the patient's contact card if they are carrying one to identify the clinical team

2. Documentation of anti-seizure medication and action a clear plan for any investigations needed

This ensures the information is clear in the notes, acted upon and flows through to discharge and follow-up. Measure anti-seizure medication (ASM) levels in patients with epilepsy who arrive at hospital with a seizure if there is any concern about adherence to, absorption of, or dose of their ASM. See point 1 for communicating the findings of ASM levels.

3. The availability of neurology advice

Make neurology advice available when needed for patients presenting with a seizure. This supports the admitting team and therefore the patient, when seizures are hard to control. Adequate neurology input was shown to improve the appropriateness of medication changes which in turn leads to better seizure control.

4. Provide dedicated sessions* for epilepsy specialist nurses to act as a point of contact and co-ordinate the pathway of care for patients who present to hospital with a seizure.

NB: This aligns with the Adult Epilepsy Specialist Nurse (ESN) Competency Framework

*The number of sessions needed should be assessed locally by determining how many patients are seen annually and the sessions could be shared across different sites as needed

5. Explain the risks associated with seizures and epilepsy

Contact with the hospital provides an opportunity to gently making people aware of risks associated with seizures which will help keep them safe. This is in line with making every contact count.

6. Communicate discharge/follow-up plans to the patient, their family/carers and healthcare teams

Improvements to the quality and content of hospital discharge summaries would help patients, their families/carers and healthcare team manage their epilepsy together.

Supporting national guidance and reports

- NICE guideline NG217: Epilepsies in children, young people and adults (2022)
[Overview | Epilepsies in children, young people and adults | Guidance | NICE](#)
- SIGN 143: Diagnosis and management of epilepsy in adults (revised 2018)
[SIGN143 Guideline](#)
- National audit of seizure management in hospitals
www.nashstudy.org.uk
- SUDEP Action
www.sudep.org/i-want-information
- Epilepsy Action
www.epilepsy.org.uk