

“I am concerned about the number of epilepsy-related deaths in prison” says Prisons and Probation Ombudsman

24 November 2025 - In a bulletin published today, the Prisons and Probation Ombudsman found that the care prisoners with epilepsy receive in prison could be improved.

The Prisons and Probation Ombudsman (PPO) investigate the deaths of prisoners, those on probation and in immigration detention, as well as deaths that occur 14 days after release from prison. From April 2024 to March 2025, they started investigations into 486 deaths where Ombudsman Adrian Usher realised the frequency in which deaths related to epilepsy were occurring.

“I am concerned about the number of epilepsy-related deaths in prison,” said Adrian. “In the past 10 years, my office has investigated 125 deaths caused by epilepsy or where the prisoner was diagnosed with epilepsy.¹ This is an area that requires more attention.

I want to raise awareness of this important area by sharing our initial learning to improve the care that prisoners with epilepsy receive.”

The bulletin highlights the potentially fatal outcomes of epilepsy in prison not being treated properly and the PPO identify several areas for HM Prison and Probation Service and NHS prison healthcare staff to consider.

The PPO shared that 0.64% of deaths in prison in the last 10 years were sudden and unexpected deaths in epilepsy (SUDEPs), however SUDEPs make up around 0.15% of deaths per year in the UK. Their findings suggest there is a lower remission rate in prison than in the community with only 18% of prisoners having not experienced a seizure in the past year.

The investigative office also found that the diagnosis of epilepsy in prisons could be improved. In 11% of reviewed cases the prisoner had not been diagnosed with epilepsy where epilepsy was found as the cause of death.

Anxiety and depression were also reported as the most common mental health conditions amongst the cases reviewed, and concerning, in 88 death investigations where the prisoner had epilepsy, 30 of these were self-inflicted.

¹ To understand the learning from epilepsy-related deaths in prisons, three categories of death types were considered:

Group 1: Where the primary cause of the prisoner’s death was epilepsy (as recorded in the post-mortem) (25 cases).

Group 2: Where the secondary cause of the prisoner’s death was epilepsy (as recorded in the post-mortem) (12 cases).

Group 3: Where the prisoner was diagnosed with epilepsy, but their primary or secondary cause of death was not epilepsy-related (88 cases).

“Our research found a higher prevalence of suicide for those diagnosed with epilepsy,” said Adrian. “Further work is necessary to understand the increased risk of suicide in prisoners with epilepsy and whether the diagnosis of epilepsy itself should be considered a risk factor.”

National Institute for Health and Care Excellence guidelines list alcohol and drug use as a potential risk factor for SUDEPs. The PPO’s researchers found that 65% of cases reviewed, revealed that the individual had a history of substance use. In some cases, they found that healthcare teams did not monitor the increase in seizure frequency appropriately.

“Prisoners are reliant on staff taking epilepsy seriously and our research revealed some concerning findings. I am grateful to healthcare colleagues who assisted in this research, and I will continue to work with NHS England and HM Prison and Probation Service closely,” said the Ombudsman.

“A better understanding of this area can improve epilepsy care and the management of epilepsy for people in prison, preventing further deaths from occurring.”

ENDS

Notes to editors:

1. This release is available at: https://ppo.gov.uk/corporate_document/i-am-concerned-about-the-number-of-epilepsy-related-deaths-in-prison-says-prisons-and-probation-ombudsman/
2. The bulletin is available at: https://ppo.gov.uk/learning_research/fatal-incident-investigations-learning-lessons-bulletin-issue-20-epilepsy/
3. Adrian Usher was appointed as Prisons and Probation Ombudsman (PPO) in April 2023.
4. The PPO is appointed by and reports directly to the Secretary of State for Justice. The Ombudsman’s office is wholly independent of the services in remit, which include those provided by HM Prison and Probation Service (HMPPS), Prisoner Escort and Custody Service, the Home Office (Immigration Enforcement), the Youth Custody Service, and those local authorities with secure children’s homes. It is also operationally independent of, but sponsored by, the Ministry of Justice (MOJ).
5. The roles and responsibilities of the PPO are set out in the Terms of Reference (ToR), the latest version of which can be found at: <https://ppo.gov.uk/document/prison-and-probation-ombudsman-terms-of-reference/>
6. The PPO has three main investigative duties:
 - complaints made by prisoners, young people in detention, offenders under probation supervision and individuals detained under immigration powers (detained individuals)
 - deaths of prisoners, young people in detention, approved premises’ residents and detained individuals due to any cause
 - deaths of recently released prisoners that occur within 14 days of release from prison (except homicide)
7. Please contact ppocomms@ppo.gov.uk if you require more information