

**Prisons &
Probation****Ombudsman**
Independent Investigations

Learning lessons bulletin

Fatal incident investigations | Issue 20

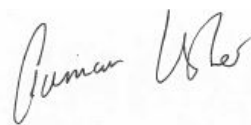
Epilepsy

Foreword

This learning lessons bulletin summarises research from Prisons and Probation Ombudsman (PPO) investigations from the past ten years where a prisoner's death was caused by epilepsy or the prisoner was diagnosed with epilepsy. Our research found the care prisoners with epilepsy receive could be improved and highlights areas requiring further work.

The PPO is acutely aware of the potentially fatal outcomes where epilepsy is not treated properly. The aim of this bulletin is to raise awareness and share initial learning. The research has identified areas that need to be explored further. The PPO will continue to work alongside the NHS and HM Prison and Probation Service (HMPPS) to formulate and oversee actions to improve the understanding of epilepsy care and the management of epilepsy for people in prison.

Our research found some concerning findings. Our research supports previous research which suggests there is a lower remission rate in prison than in the community. In the cases we have investigated, National Institute for Health and Care Excellence (NICE) guidelines for epilepsy are not always being followed. In cases where care plans were mentioned in our investigation report or the clinical review, and the prisoner had an epilepsy diagnosis, only 38% had a documented care plan. We also found that there is often not appropriate monitoring of seizures or follow-ups where medication adherence is poor. Where medication adherence protocols were in place, they are not always being followed. Our research also found that 74% of prisoners in our sample had a mental health condition and 65% had a history of substance use. Further work is needed to improve the care of epilepsy in prisons.

**Adrian Usher**

Prisons and Probation Ombudsman

Context and data

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).¹

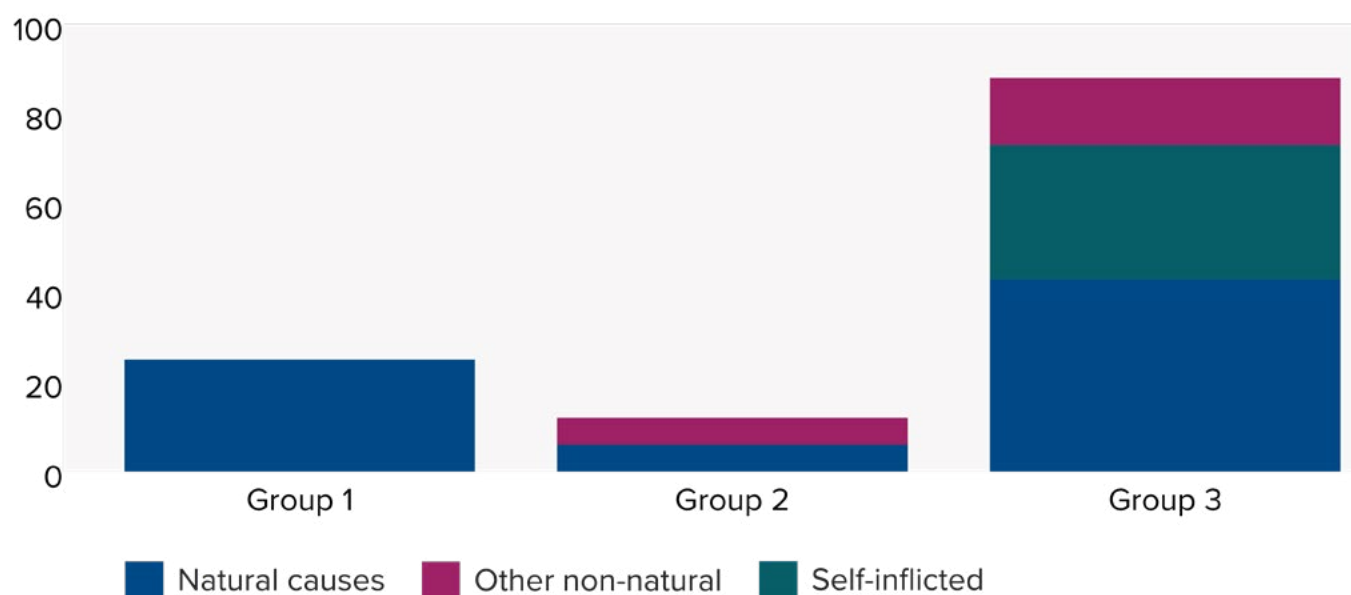
Group 3: Where the prisoner was diagnosed with epilepsy, but their primary or secondary cause of death was not epilepsy-related (88 cases).²

In the past 10 years, the PPO has investigated 125 deaths that fell into one of these three categories.³ For each group, the PPO report and clinical review was analysed.

Death classification

All 25 deaths in group 1 were natural causes. Of the 12 deaths in group 2 (where the secondary cause of death was epilepsy), six were other non-natural (four were drug-related) and six were natural causes. Of the 88 deaths in group 3 (cases where the prisoner had an epilepsy diagnosis but did not die from epilepsy) 43 of the deaths were natural causes, 30 were self-inflicted and 15 were other non-natural (13 were drug related).

Prisoner deaths reviewed for research by group from April 2015 to April 2025



1 Within group 1 and 2 not all prisoners had a diagnosis of epilepsy. In group 1, 88% of prisoners had an epilepsy diagnosis. In group 2, 83% had a diagnosis.

2 Due to the limited clinical records we had access to, we were unable in all cases to gain a detailed understanding of how or when all these diagnoses came about.

3 The research looked at deaths that we were notified of between 16 April 2015 and 16 April 2025 that also had an initial report available. Only deaths where the individual was in prison were included, i.e., post-release deaths and any deaths from approved premises were excluded from this research.

Diversity data

All prisoners in groups 1 and 2 were male. In group 3, 7 prisoners were female (7.9%).

Of the 125 cases, 10% of prisoners were between the ages of 21 and 30. 21% were between 31 and 40, and 32% were between 41 and 50. Except for one death where the prisoner was 16, the rest were over 50.

Of the 25 cases where the primary cause of death was epilepsy (group 1), 15 prisoners (60%) were white. Six prisoners (24%) were black or black British. The population of black or black British prisoners is around 12%. However, when combining all three groups together (125 investigations), black or black British prisoners made up 7% of deaths.

Epilepsy in prisons: SUDEP, seizure control, diagnosis and NICE guidelines

It is estimated that cases of sudden and unexpected death in epilepsy (SUDEP) make up around 0.15% of deaths a year in the UK. From post-mortem reports of deaths in prisons from the past 10 years, 0.64% of deaths in prison were SUDEP cases. People in custody typically have more complex health needs than the general population and, due to the lower average age in prisons compared to the community, you would also expect a higher percentage of deaths to be caused by conditions such as SUDEP. Some studies have found a three to four times higher prevalence of epilepsy in prisons than in the community.⁴

Nevertheless, the higher rate of SUDEP in prisons is concerning. For one third of SUDEP cases, there is a witnessed seizure or signs of a recent seizure close to the time of death.⁵ By controlling an individual's seizures through treatment, the risk of SUDEP is reduced. It is important that prisoners with epilepsy receive appropriate care to control their seizures as well as possible and reduce their risk of SUDEP.

It is estimated that up to 70% of people living with epilepsy could live seizure-free if properly diagnosed and treated.⁶ A study from the UK in 2004, using a sample of 1,652 people with epilepsy, found 51.7% had not experienced a seizure in the preceding year.⁷ Research into UK prisons has found much lower percentages of prisoners with epilepsy are seizure-free. Research from 2022 found only 12.7% of prisoners with epilepsy were seizure-free in the last 12 months.⁸ More recent research found only 0.2% of prisoners with a label of epilepsy were seizure-free in the last 12 months.⁹ From our 125 death investigations, we found only 18% had not experienced a seizure in the past year, 56% had, and for the remaining 26% of prisoners it was unclear. The poor seizure control rate among the sample may suggest that these prisoners could have benefited from specialist input and a review of their treatment.

Our review also found that the diagnosis of epilepsy within prisons could be improved. In 11% of the cases from group 1 and 2 (where the primary or secondary cause of death was epilepsy) the prisoner had not been diagnosed with epilepsy. We found examples where prisoners were receiving medication for seizures and it was widely considered they

4 Thomasson, Rachel., et al (2022), Audit of epilepsy healthcare provision in a large UK category B prison, available at: <https://www.sciencedirect.com/science/article/pii/S1059131122000905#sec0015>

5 Epilepsy Foundation, Early death and SUDEP, available at: <https://www.epilepsy.com/complications-risks/early-death-sudep>

6 World Health Organisation (2024), Epilepsy, available at: <https://www.who.int/news-room/fact-sheets/detail/epilepsy>

7 Moran, N. F., et al (2004), 'Epilepsy in the United Kingdom: seizure frequency and severity, anti-epileptic drug utilization and impact on life in 1652 people with epilepsy', available at: <https://pubmed.ncbi.nlm.nih.gov/15276147/>

8 Thomasson, Rachel., et al (2022), Audit of epilepsy healthcare provision in a large UK category B prison, available at: <https://www.sciencedirect.com/science/article/pii/S1059131122000905#sec0015>

9 Bellass, Sue., et al (2024), 'Understanding and improving the quality of primary care for people in prison: a mixed-methods study', available at: <https://www.journalslibrary.nihr.ac.uk/hsdr/GRFV4068#plain-language-summary>

had epilepsy, yet they never received a formal diagnosis. In some cases, healthcare teams could have done more to determine whether the prisoner had epilepsy.

NICE guidelines on epilepsy require that a person with epilepsy is provided with a copy of their care plan. In cases where it was mentioned, and where the prisoner had an epilepsy diagnosis, only 38% of prisoners had a documented care plan. Clinical reviewers do not always assess whether a prisoner's epilepsy care was equivalent to care they would receive in the community. For the entire sample, it was assessed in 40% of cases. Among those, only 58% were found to have care equivalent to that available in the community. A care plan should include key information such as triggers that may provoke someone's seizures, their regular medication, and an emergency care plan including instructions about the timing and administration of rescue medication where necessary. Without a care plan, it is difficult for prison or healthcare staff to appropriately support a prisoner with epilepsy.

Of the prisoners that had an epilepsy diagnosis, only 42 prisoners had been at the prison they died in for over a year. In 36% of these cases, there were records that the prisoner had a yearly epilepsy review. Of the prisoners who did not receive a yearly epilepsy review, most had other comorbidities (a mental health condition, substance use or learning difficulties) which may have suggested they should have received an annual review.

Lessons to be learned

- Healthcare should ensure all prisoners with a diagnosis of epilepsy have a care plan and a copy is provided to them. They should also consider if the prisoner has a serious comorbidity and whether they should have an annual epilepsy review.

The following sections explore the themes we found from our research with case studies of deaths we have investigated.

Epilepsy, mental health and self-inflicted deaths

In 74% of all 125 investigations reviewed for this research, the prisoner had a mental health condition. Anxiety and depression were the most common. 30% of all prisoners had anxiety and 54% had depression. When discussing epilepsy within the prison population, it is also important that healthcare considers the potential that the prisoner's seizures are dissociative and the potential links to trauma. In many cases, we also saw a relationship between a prisoner's poor mental health and a disruption to their epilepsy care. 22% of prisoners with a mental health condition refused to attend hospital appointments and 26% did not comply with medication.

Our analysis also identified several self-inflicted deaths among individuals diagnosed with epilepsy. Within group 3 (prisoners who were diagnosed with epilepsy, but epilepsy was not the cause of their death) 34% died by suicide. In comparison, 26% of all deaths in prison were self-inflicted in the last 10 years, suggesting a higher prevalence of suicide for those diagnosed with epilepsy. Previous research has also found that people with epilepsy are twice as likely to die by suicide as people without epilepsy. While the risk is still generally low, it was found to be increased in comparison to people without epilepsy.¹⁰ Further work is necessary to understand the increased risk of suicide in prisoners with epilepsy and whether a diagnosis of epilepsy should be considered a risk factor. In the following case study, changes to epilepsy medication caused the prisoner significant distress.

10 Epilepsy Action (2022), Increased risk of death from suicide and accidents, available at: <https://www.epilepsy.org.uk/news/study-finds-increased-risk-of-death-from-suicide-and-accidents-in-people-with-epilepsy>

Case study 1

Ms A was prescribed clonazepam in the community for seizures and back pain. Her epilepsy diagnosis had not been confirmed, however she had received this medication for some years (including at the prison she had transferred from) and had a confirmed repeat prescription from her community GP. The prison GP was concerned that she was benzodiazepine-dependent and arranged for a reduction of her medicine. The decision caused Ms A considerable distress; she felt anxious and worried about experiencing seizures. Ms A was managed on an ACCT (standing for Assessment, Care in Custody and Teamwork) – a process for suicide and self-harm prevention. However, no member from healthcare participated in the ACCT process. The GP who reviewed Ms A's medication on the day of her death was also unaware that she was on an ACCT. Ms A died by hanging. The clinical reviewer criticised the fact that nobody from the healthcare team was involved in the ACCT process. NICE guidelines also require effective communication between healthcare professionals involved in the care of people with epilepsy and a mental health condition.

Lessons to be learned

- Effective communication is needed between healthcare professionals involved in the care of people with epilepsy and a mental health condition that impacts their seizure control.

Stress and the effect on epilepsy

As might be expected, in 75% of the cases we reviewed, there was evidence that the prisoner had experienced stress relating to their imprisonment. This included worrying about cell/prison transfers, being away from family, or being worried about upcoming sentencing. Existing research suggests that stress can negatively impact an individual's epilepsy, making seizures and fatalities more likely.¹¹

In cases where the individual's primary or secondary cause of death was epilepsy-related, 11% of individuals died just days after entering the prison where they died, and a further 11% died just weeks after entering the prison. The stressful effects of entering a prison could have had some potential impact here. In some of the cases we reviewed, stress directly impacted the number of seizures the prisoner had.

Case study 2

Mr B was sentenced to five years in prison. He had epilepsy and reported regular seizures. He was referred for specialist opinion and seen regularly by prison GPs to review his medication. He was also assessed by the mental health team for stress and anxiety and was prescribed antidepressants. His stress and anxiety often triggered his seizures. Mr B was then moved prison.

When he arrived at his new prison, he told the nurse he had epilepsy. Two days after his arrival, he rang his cell bell. He told the officer that he felt "something" might be coming on and explained that his seizures were brought on by stress and he felt stressed following his recent prison transfer. Staff decided he did not need urgent help. He was found later that day lying on his bed unresponsive. The post-mortem concluded Mr B died of SUDEP.

11 Espinosa-Garcia, Claudia., et al (2021), 'Impact of Stress on Epilepsy: Focus on Neuroinflammation – A Mini Review', available at: <https://www.proquest.com/docview/2548737072?sourcetype=Scholarly%20Journals>

The clinical review commented that outside of the omission to provide medication when the prisoner was transferring, there were examples of good practice from the sending prison, including regular GP reviews and referrals to epilepsy specialists. Stress triggered his seizures and Mr B received extensive support from the mental health team, bereavement counselling and access to emotional awareness groups.

Substance use

In 65% of the cases we reviewed, the individual had a history of substance use. Substance use can also cause seizures. There was some indication of seizures not being taken as seriously where the individual used substances and, in some cases, staff did not follow local protocols.

NICE guidelines list alcohol and drug misuse as a potential risk factor for SUDEP. It is important that prisoners with epilepsy that use substances receive appropriate specialist care from both epilepsy specialists and substance use teams. There should also be collaboration between healthcare and substance use services. Further work is needed to ensure prisoners are educated on the risks of using substances which is exacerbated when a prisoner has epilepsy.

There is also the risk that some epilepsy medication can be misused (sold to other prisoners, traded, or taken in larger doses than prescribed). We found evidence of this in 14 investigations. The Royal College of General Practitioners has issued guidance on Safer Prescribing in Prisons. The guidance has a useful chapter on epilepsy which sets out the anti-epileptic drugs at risk of diversion in prison.

Case study 3

Mr C transferred prisons and was seen by a nurse for reception screening. The nurse referred him to the GP who prescribed Mr C his epilepsy medication and requested a lower bunk for him. He consistently did not collect his daily epilepsy medication. His illicit drug use increased, as did his seizure frequency. His post-mortem confirmed he died from SUDEP.

The clinical reviewer commented that while he was warned of the risk of non-compliance with anti-seizure medication and referred to the substance misuse team, it was not clear that he was warned that non-compliance with medication, alongside substance use, potentially increased his risk of SUDEP. The clinical reviewer also said that the prisoner should have been reviewed regularly by the prison's Multi-Professional Complex Case Clinic (MPCCC) as a prisoner whose behaviour was placing him at greater risk.

Lessons to be learned

- Substance use is a risk factor for SUDEP. Where prisoners with epilepsy are using substances, healthcare must work with other specialists, such as substance misuse teams, to address this risk.

Addressing poor medication adherence

For many people with epilepsy, taking medication can help manage their condition effectively. Of the 125 cases reviewed, 34% were taking their medication, 28% were not and for the remaining 37% it was unclear. The NICE guideline lists non-adherence to medication as a risk factor for SUDEP.

There may be various reasons why a prisoner is not taking their medication. Prisoners may be being bullied for their medication, non-adherence may be related to a prisoner's poor mental health, the prisoner may not understand the risks associated with failing to take their medication, or they may be worried about side effects. The Royal College of General Practitioners' guidance on Safer Prescribing in Prisons sets out the recommended medication for epilepsy and their potential side effects. In some of the cases, we found positive practice where there were frequent discussions with the prisoner about their non-adherence and the risk of non-compliance. However, in some cases there was no system in place for when prisoners repeatedly failed to collect their medication. In others, such as the following case study, staff failed to follow the procedures that were in place.

Case study 4

For long periods of time, Mr D refused to take his epilepsy medication and experienced regular seizures. He died of SUDEP. The healthcare provider's medication refusal protocol required that if a prisoner refused to take medication five times in a row, it should prompt a GP review. While healthcare staff sometimes followed this, GP appointments were not always made where this threshold was met. The protocol also required that an appointment should be arranged sooner if the medication was critical. The clinical reviewer considered that Mr D's medication was critical to managing his epilepsy, so GP appointments should have been made more frequently and with more urgency.

To manage the risk of Mr D, healthcare staff arranged to supervise him each time he took his medication. Despite this, the nurse found extra medication in his cell two days before his death. The nurse told the investigator that, on the morning of Mr D's death, he did not check Mr D had taken his medication before he left the cell. The clinical reviewer was concerned that the arrangements to supervise Mr D's medication were not sufficiently robust.

It is important that for prisoners with epilepsy who are not taking their medication, there is a system in place to address this which is followed. Where prisoners fail to take their medication, this increases their risk of SUDEP.

Lessons to be learned

- Non-adherence to medication is a risk factor for SUDEP. Prison healthcare teams should have robust medicine management processes for escalating and managing poor adherence with anti-seizure medication.

Increases in seizure frequency

We found some examples where a prisoner's seizure frequency increased. Despite this, healthcare teams did not monitor the seizures or consider whether to refer the prisoner for specialist treatment. We found 11 examples where a prisoner's seizure frequency increased, and the clinical review determined that action could have been taken to address this. Some of these prisoners died from SUDEP. It is important that increases in seizures are recorded and, where necessary, treatment is reviewed. SUDEP is more likely in people with frequent seizures.

Case study 5

Mr E had a diagnosis of epilepsy and transferred prisons. Before transferring, and at Mr E's last neurology review, it had been decided his medication would increase. At the new prison, Mr E had a medication review due to his ongoing seizures. He told the GP he was having five seizures a week. The GP increased his medication in line with what had been agreed at his last neurology review (the increase had not been implemented) and planned to review him in four weeks. There is no evidence that this review happened. The clinical review criticised the fact that at this appointment, healthcare did not review his epilepsy care plan or implement a plan to monitor his seizures. The clinical reviewer considered the failure to actively monitor Mr E's seizures was a missed opportunity to assist the neurologist with Mr E's treatment.

A few months later, Mr E was found unresponsive in his cell. He died from SUDEP.

It is important that healthcare have records of a prisoner's seizures. Further partnership working between the NHS and HMPPS is needed to consider how seizures can be best monitored and recorded. Further work is also needed to consider the use of pathways to ensure prison healthcare teams can escalate a prisoner's epilepsy care where necessary.

Continuity of epilepsy care

While reviewing the cases, we found repeat issues with the continuity of care prisoners with epilepsy received. Care was often disrupted when a prisoner transferred prison. In the 125 investigations analysed, 32% had transferred prisons in the 12 months before their death. The PPO considers that for some prisoners with epilepsy, and in certain circumstances, it may be inappropriate for them to be transferred. The PPO will be working with the NHS and HMPPS to consider this issue further and where the use of a medical hold may be appropriate.

For groups 1 and 2 (where the individual's primary or secondary cause of death was epilepsy), 22% of individuals died within days or weeks of entering the prison in which they died, highlighting the importance of providing appropriate care as soon as a prisoner enters prison. According to NICE guidance (NG57), a prisoner should have a first stage health assessment at reception. The guidance requires a second stage health assessment to be completed within seven days of the first stage health assessment. These screenings should explore whether the prisoner has epilepsy or a history of seizures. In the reports where it was mentioned, 101 prisoners received the first stage health assessment and only 52 received the second stage. In some cases, we saw the second stage health assessment being completed months after the prisoner had first entered prison. Healthcare teams should review patients with a history of seizures and refer them to neurology where the diagnosis is not confirmed or if seizure control is poor. The case study below highlights the importance of ensuring continuity of care.

Case study 6

Mr F had epilepsy. At the first prison he stayed at (for just under two years), he had experienced 24 seizures. During this time, he had an epilepsy care plan, and his medication was reviewed. He then transferred prison.

The day after transferring, the nurse completed an initial health screen. She recorded that Mr F had epilepsy. That day, Mr F missed his epilepsy review at the hospital. It had been booked while he was at the previous prison, but the staff at his current prison were not informed about the appointment. Mr F did not have his scheduled secondary health screen due to a lack of staff. Mr F was found dead by an officer completing welfare checks 12 days from when he had transferred to the prison.

The clinical reviewer found the physical care Mr F received was not always equivalent to what could be expected in the community. Prison Service Order 3050 on the continuity of healthcare for prisoners says that information on continuing care should be conveyed to another prison on transfer.¹² This may require communicating directly with the receiving healthcare team in advance of transfer. There was no healthcare handover when Mr F transferred. This meant information about his epilepsy risk and a recent hospital admission (unrelated to his epilepsy) were not shared with the receiving prison. It also meant Mr F missed a consultant epilepsy review. He also arrived at the prison without some critical medications.

We reviewed other cases where prisoners transferred without their epilepsy medication which often meant they missed doses of critical medication. In another case, we found that where a prisoner was admitted to hospital in relation to their seizures, healthcare did not assess them for over a week and failed to chase an accompanying report from the hospital.

While there is significant pressure on prisons, the proper transfer of information about a prisoner's condition, and ensuring the prisoner transfers with their medication, can often be crucial.

Lessons to be learned

- Healthcare should ensure prisoners with epilepsy are transferred with their medication and, where necessary, communicate directly with receiving healthcare teams. Receiving healthcare teams should review all medical information including any existing care plans.
- Healthcare should prioritise an early review of patients with a history of seizures in prison and refer them to neurology if the diagnosis is not confirmed or if seizure control is poor.

12 HMPPS and MOJ (2006), Ensuring continuity of healthcare for prisoners: PSO 3050, available at: <https://www.gov.uk/government/publications/ensuring-continuity-of-healthcare-for-prisoners-pso-3050>

The importance of prison staff

Prisoners are often reliant on prison staff taking their epilepsy seriously and acting on their behalf to ensure they receive appropriate care. This is particularly true in emergency situations.

Case study 7

On the night of Mr G's death, his cellmate rang the emergency bell concerned that Mr G was having a seizure. The cell mate said that Mr G was making groaning and choking noises, and he did not notice Mr G moving in the bunk bed above him. The bell was answered by an officer approximately 40 minutes later.

During our investigation, the officer said he had asked the cellmate to see if he was still having a seizure, if he was bleeding, or if he had urinated. The officer said the cellmate noted no movement to indicate that Mr G was in distress and from what he could see outside the cell, he believed Mr G was sleeping. During the investigation, the cellmate said that the officer had told him that if Mr G was having a seizure, it would wear off by the morning.

When the cellmate woke up in the morning, he checked Mr G, who was unresponsive. The post-mortem established Mr G's death was consistent with epilepsy. The prison's policy made clear that epileptic seizures are an example where a code blue should be called. If the officer had called a code blue, healthcare would have attended, and the control room would have called for an ambulance.

The case highlights the importance of prison staff and responding appropriately to seizures. In emergency situations and in prisons generally, healthcare is dependent on prison staff. In 22% of the investigations we reviewed, prison staff missed an opportunity to intervene sooner (through welfare or roll checks). Further work is required to ensure that prison staff are aware of what to do when a prisoner is having a seizure.

The PPO has been critical in cases where wing staff have not realised prisoners having a seizure needed medical attention, instead they thought the prisoner was asleep. The sharing of risk information is another area which should be explored further. Where prisoner consent is sought and received, it may be appropriate for high level information about risk (as opposed to detailed medical information) to be shared with operational staff. We are aware that some prisons are using epilepsy registers.

Epilepsy and cell arrangements

Where cell sharing was mentioned and where the prisoner had an epilepsy diagnosis, we found that in 69% of cases the prisoner was not sharing a cell. Some prisons have policies whereby prisoners with epilepsy will not share cells to avoid placing responsibility on other prisoners. In our review, we did sometimes find that where a prisoner with epilepsy was sharing a cell, there was inappropriate responsibility placed on the prisoner. For example, in the case of Mr G, the cell mate was asked by the officer to provide a clinical assessment of his cell mate. This can impact the wellbeing of the cell mate and is not appropriate for either prisoner.

However, there is a clear benefit in a prisoner with epilepsy sharing a cell as their cell mate can quickly raise an alarm if a prisoner is having a seizure. NICE guidelines suggest that sleeping alone without supervision is a risk factor for SUDEP.

In some cases, it will clearly not be appropriate for a prisoner with epilepsy to share a cell (where there are clear safety concerns). The cell mate should also not be responsible for making medical determinations. However, further work is needed to explore the use of single cells for prisoners with epilepsy and local policies which prevent prisoners with epilepsy cell sharing.

While reviewing our cases, we also found a few examples where prisoners with epilepsy, or prisoners experiencing seizures, were placed on the top bunk of beds. This increases the potential risk of injury to the prisoner and should be avoided. In some cases, it had been requested by healthcare that the prisoner should be placed on a lower bunk because of their epilepsy, but the prisoner had still been placed on a top bunk. The situation in prisons is often complex and there may be other reasons why a prisoner allocated a lower bunk is sleeping on the top one. Nevertheless, prisoners with epilepsy are at greater risk of harm when sleeping on the top bunk.

Lessons to be learned

- Prisoners suffering seizures should not be located on top bunks.

Summary of lessons to be learned

Epilepsy in prisons: SUDEP, seizure control, diagnosis and NICE guidelines

- Healthcare should ensure all prisoners with a diagnosis of epilepsy have a care plan and a copy is provided to them. They should also consider if the prisoner has a serious comorbidity and whether they should have an annual epilepsy review.

Epilepsy, mental health and self-inflicted deaths

- Effective communication is needed between healthcare professionals involved in the care of people with epilepsy and a mental health condition that impacts their seizure control.

Substance use

- Substance use is a risk factor for SUDEP. Where prisoners with epilepsy are using substances, healthcare must work with other specialists, such as substance misuse teams, to address this risk.

Addressing poor medication adherence

- Non-adherence to medication is a risk factor for SUDEP. Prison healthcare teams should have robust medicines management processes for escalating and managing poor adherence with anti-seizure medication.

Continuity of epilepsy care

- Healthcare should ensure prisoners with epilepsy are transferred with their medication and, where necessary, communicate directly with receiving healthcare teams. Receiving healthcare teams should review all medical information including any existing care plans.
- Healthcare should prioritise an early review of patients with a history of seizures in prison and refer them to neurology if the diagnosis is not confirmed or if seizure control is poor.

Epilepsy and cell arrangements

- Prisoners suffering seizures should not be located on top bunks.

Acknowledgements

This work has been heavily supported by healthcare professionals who have provided us with feedback on our initial research and are helping us develop the actions for further work. The PPO is grateful for their work in this important area.

About the data

The research reviewed deaths that we were notified of between 16 April 2015 and 16 April 2025 where we had an initial report available. Only deaths where the individual died in prison were reviewed.

Three groups were created:

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).

Thematic analysis

The research team reviewed each group separately. Each researcher reviewed different cases and highlighted key parts of the report. They then applied three-level coding to identify key themes. A meeting was held with all researchers for each group to compare these and ensure validity.

Quantitative analysis

A working group designed a questionnaire to review the cases. The group involved the research team, investigators, and NHS England colleagues. We discussed the questions and any key themes that would be quantifiable.

Cases from the groups were allocated and the questionnaire form was filled out. The clinical review and PPO reports were reviewed to complete the form.

The data was collated and the results for each question were analysed. On occasion, the responses to more than one question were analysed together (for example, of the prisoners who had a mental health condition, how many were not taking their medication). Some totals may not add up to 100% due to rounding.



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