**Premature mortality in people with epilepsy**

**Overview:** People with epilepsy are at increased risk of premature death, with a mortality rate that is 2–3 times higher than that for the general population (Cockerell et al. 1994). Premature death in people with epilepsy can be the result of disease-linked factors (such as status epilepticus), sudden unexpected death in epilepsy (SUDEP) or underlying disease (for example, stroke or brain tumour, National Sentinel Clinical Audit of Epilepsy-Related Death 2002).

In 2012, epilepsy or status epilepticus was the primary cause of 986 deaths in England and Wales, almost half of which were in people under the age of 55 years (Office for National Statistics 2013). However, people with epilepsy are also at increased risk of death from external causes such as suicide (Bell et al. 2009) and accidents resulting from seizures, including drowning (van den Broek et al. 2004).

See the NICE Evidence Services topic page on epilepsies for a general overview of this condition.

**Current advice:** NICE guidance on the epilepsies recommends that children, young people or adults with epilepsy, and their family and/or carers, should be provided with tailored information on the person’s relative risk of SUDEP. It advises that the risk of SUDEP can be minimised by optimising seizure control and being aware of the potential consequences of nocturnal seizures.

The guidance also recommends that healthcare professionals should be aware of the higher risk of mortality for children, young people and adults with learning disabilities and epilepsy and discuss these with them and their families and/or carers.

The NICE Pathway on epilepsy brings together all related NICE guidance and associated products on the condition in a set of interactive topic-based diagrams. The NICE Evidence Update on the epilepsies highlights and provides commentary on selected new evidence published since the NICE guidance was issued.

**New evidence:** Fazel et al. (2013) assessed premature mortality, in particular from external causes, and the role of psychiatric comorbidities in people with epilepsy. This total population study used the Swedish national Patient Register to identify people with epilepsy (n=69,995) and whether they had a primary or secondary diagnosis of any psychiatric condition. These patients were matched by age and sex to up to 10 general population controls (n=660,869), and to unaffected siblings (n=81,396).

Deaths and their causes were identified during an average follow-up of 9 years (interquartile range 5–18 years).

People with epilepsy had a substantially increased risk of premature mortality compared with general population controls (OR adjusted for sociodemographic confounders [aOR]=11.1, 95% CI 10.6 to 11.6) and unaffected sibling controls (aOR=11.4, 95% CI 10.4 to 12.5). People with epilepsy had an increased risk of premature death from natural causes (aOR=15.5, 95% CI 14.6 to 16.4 compared with the general population). The most common natural causes of death were neoplasms and
diseases of the nervous system, both of which could potentially be related to underlying disease processes.

People with epilepsy were also at higher risk of premature death from external causes than the general population (aOR=3.6, 95% CI 3.3 to 4.0) and siblings (aOR=3.2, 95% CI 2.7 to 3.7). The risk of death from external causes was highest for non-vehicle accidents (such as a fall or drowning; aOR=5.5, 95% 4.7 to 6.5 compared with the general population), followed by suicide (aOR=3.7, 95% CI 3.4 to 4.2), assault (aOR=2.8, 95% CI 1.6 to 4.8) and vehicle accidents (aOR=1.4, 95% CI 1.1 to 1.8).

People with epilepsy had a higher prevalence of psychiatric diagnoses than the general population (40.7% versus 10.3%). The risk of death from external causes in people with epilepsy who had a lifetime psychiatric diagnosis was 10 times higher than in people with no epilepsy and no psychiatric disorders (aOR=10.6, 95% 9.2 to 12.2). The risk of premature death was particularly high among patients with epilepsy who had depression (aOR=13.0, 95% 10.3 to 16.6) or substance misuse (aOR=22.4, 95% 18.3 to 27.3).

**Commentary:** “It has been suspected for some time that people with epilepsy have excess mortality as well as high levels of psychiatric comorbidity. This large, Swedish, population cohort study shows that accidents and suicides are excessively high in people with epilepsy and associated with depression and substance misuse. Underlying neuro-genetic syndromes and other confounding variables may contribute to the raised mortality rate. However, these syndromes are rare, so the results of this study are probably generalisable to the UK population.

“These results may influence clinical practice, in particular case identification for psychiatric disorders in people with epilepsy and the use of anticonvulsant medications, which also have mood-stabilising effects. Whether case identification should take place in primary or secondary care needs to be debated. Some might argue that primary care doctors are better equipped than neurologists to undertake case identification, but either way the resource implications are likely to be considerable. Potential cost savings may be realised from case identification if earlier psychiatric intervention could improve the employment prospects of people with epilepsy (current unemployment rates amongst people with epilepsy are 2–3 times the average), but this remains speculative.” – Professor Adrian Wills, Honorary Clinical Associate Professor and Consultant Neurologist, Nottingham University Hospital NHS Trust

**Study sponsorship:** Wellcome Trust, the Swedish Prison and Probation Service and the Swedish Research Council.

---

**About this article:** This article appeared in the March 2014 issue of the Eyes on Evidence e-bulletin. This free monthly e-bulletin from NICE Evidence outlines interesting new evidence and what it means for current practice. They do not constitute formal NICE guidance. The opinions of contributors do not necessarily reflect the views of NICE.

To receive the Eyes on Evidence e-bulletin, please complete the online registration form.