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Deputy Paul Murphy, TD  
Dáil Éireann  
Leinster House  
Kildare Street  
Dublin 2

**RE: PQ 46326/23**

**To ask the Minister for Health if he is aware of a call by an organisation (details supplied) for the development and implementation of a national strategy to reduce epilepsy-related deaths; if he will action this strategy; and if he will make a statement on the matter**

**Details:** Epilepsy Ireland. On SUDEP Action Day (18th October), - by visiting the SUDEP section of our website. It is estimated that between 21-44 people pass away due to SUDEP in Ireland each year; while in total, it is estimated that there are approximately 130 epilepsy-related deaths in Ireland each year. In addition to SUDEP, epilepsy-related deaths include those from status epilepticus (a prolonged seizure), drowning or injury associated with a seizure.

Dear Deputy Murphy,

The Health Service Executive has been requested to reply directly to you in relation to the above parliamentary question, which you submitted to the Minister for Health for response. I have consulted with the National Clinical Programme for Neurology (NCPN) on your question and have been informed that the following outlines the position.

The HSE's National Clinical Programme for Neurology (incorporating Epilepsy) is committed to improving access, quality and value for patients with neurological conditions, including epilepsy, across the spectrum of ages from paediatrics to the elderly, with three core aims:

1. To improve access to expert care and information;
2. To improve the quality of care across the healthcare spectrum;
3. To improve value-conscious care, by shifting care where possible from hospital-based care to the community, aligned to Slaintecare.

The work of the Epilepsy's workstream of National Clinical Programmes for Neurology is towards lessening the morbidity and mortality of Epilepsy.

The HSE's Epilepsy Model of Care (2016)<sup>1</sup> sets out a vision for the transformation of epilepsy care in Ireland to provide the best patient centred care for all people with epilepsy in the right place, at the right time, sharing the best available information. The model takes an integrated approach to epilepsy healthcare. It spans primary and acute settings, reflects the varying needs of people with chronic disease and acts as a blueprint for epilepsy services to ensure that the best value and most appropriate care is provided for all.

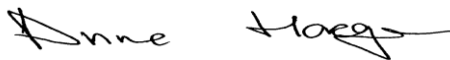
Additionally, The National Clinical Programme for Neurology (incorporating Epilepsy) has published a HSE Practice Guide for the Management of Women with Epilepsy (2018)<sup>2</sup>.

Work of the HSE's National Clinical Programme for Neurology (incorporating Epilepsy) has led to advances in clinical care and epilepsy research in Ireland. Research in epilepsy is fostered through both public and private initiatives disseminated through clinical services. Research is ongoing with Sudden Unexpected Death in Epilepsy (SUDEP). The Neurophysiology Department in St. James' Hospital Dublin, in collaboration with Epilepsy Ireland, the Irish Institute of Clinical Neuroscience and the Health Research Board, are researching the incidence of SUDEP in Ireland with research nursing staff employed in this work. Additionally, neurophysiology representatives from Ireland sit on a Steering Committee of an international multi-centre case control study of SUDEP, which is being led by a Lead Investigator based in New Zealand.

The NCPN cannot comment on the work of individual advocacy groups, such as Epilepsy Ireland, with respect to Sudden Unexpected Death in Epilepsy (SUDEP).

I trust this information is of assistance to you, but should you have any further queries please do not hesitate to contact me.

Yours sincerely



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**Anne Horgan**  
**General Manager**

#### References

1. <https://www.hse.ie/eng/services/publications/clinical-strategy-and-programmes/epilepsy-model-of-care.pdf>
2. <https://www.hse.ie/eng/about/who/acute-hospitals-division/woman-infants/clinical-guidelines/practice-guide-for-mgt-of-women-with-epilepsy.pdf>