

THE EPILEPSY DEATHS REGISTER

Making every epilepsy death count



SUPPORTING THE BEREAVED AFTER AN EPILEPSY-RELATED DEATH

Providing information for research to prevent future deaths

THE EPILEPSY DEATHS REGISTER (EDR)

is a safe and secure platform for professionals and the bereaved, to provide information about the deaths of people with, or suspected to have had, epilepsy.

Launched in 2013 by SUDEP Action, the Register sensitively involves the bereaved in research, with support available throughout the process and beyond. Each report is treated confidentially, all data used is anonymised.

The EDR and SUDEP Action work together as a unique central point for support, research and registries for all epilepsy deaths. Information shared via the EDR, helps to improve services for people with epilepsy and the bereaved, and ultimately helps to reduce deaths from epilepsy.

WHY THE EDR IS NEEDED

Epilepsy is the most serious neurological condition, leading to an increased risk of death. Sudden Unexpected Death in Epilepsy (SUDEP) accounts for around half of these deaths.

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There are at least 21 epilepsy related deaths every week in the UK



At least 42% of these deaths are potentially avoidable with better knowledge and access to services

42%

FURTHER INFORMATION:

Online: epilepsydeathsregister.org

Phone: 0330 088 1220

Email: team@epilepsydeathsregister.org

WHAT TO REPORT

The death of a person who had or was suspected to have epilepsy, including:

- SUDEP (Sudden Unexpected Death in Epilepsy)
- a sudden death in someone with evidence of a seizure that cannot be explained
- deaths reported as status epilepticus
- accidental deaths
- deaths from suicide
- deaths reported as cause unknown

WHEN TO REPORT

As soon as you feel able to, you do not have to wait until any investigations are complete. If you are unsure if you have enough information, please contact the EDR team.

WHO CAN REPORT

Anyone who is over 18, with information about a death. More than one person can report the same death as they may have different information to give.

- Relatives, flat-mates and friends
- Health professionals; carers and social workers
- Coroners; procurators fiscal and pathologists

SUPPORTING THE BEREAVED THROUGH THE INQUEST PROCESS

SUDEP Action exists to increase awareness of epilepsy risks and tackle all epilepsy deaths. With over 20 years' experience, it is the only UK charity with specialist expertise in supporting and working alongside anyone bereaved by epilepsy.

The free support service is tailored, led by what the bereaved need and want - which can include counselling, advocacy, information, advice and involvement in research, through The Epilepsy Deaths Register.

SUDEP Action can assist and empower the bereaved in their interactions with the coronial service and other agencies, which can be combined with ongoing support.

Contact: **01235 772852**

email: **support@sudep.org**