THE EPILEPSY DEATHS REGISTER
Making every epilepsy death count

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.

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.

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

FURTHER INFORMATION:

Online: epilepsydeathsregister.org
Phone: 0330 088 1220
Email: team@epilepsydeathsregister.org

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.

epilepsydeathsregister.org

SUDEP Action, registered charity
1164250 (England & Wales), SC047223 (Scotland)
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

The Epilepsy Deaths Register is owned and managed by SUDEP Action. The research is carried out by the EDR team in collaboration with Newcastle University. The Register is endorsed by leading experts in epilepsy mortality.