

Epilepsy Specialist Nursing Service

Adult Disability Services

Sudden Unexpected Death in Epilepsy (SUDEP) Information for Families and Carers



eQUALITY
for people with learning disabilities

www.hertfordshire.gov.uk



Hertfordshire



SUDEP is the term used when someone with a diagnosis of Epilepsy dies suddenly, without warning and following post mortem no other cause of death can be found.

Although it is rare (approx. 1 in 1,000 people with epilepsy die from SUDEP each year, (SUDEP Action 2013), it is a condition which we must know about.

The exact causes of SUDEP are still being investigated. What we do know is that during a seizure there is often a change in the individuals breathing and / or heart rhythm. This is usually manageable for the individual however where a serious change happens, for example a large drop in oxygen in the blood, this may be a trigger for SUDEP.

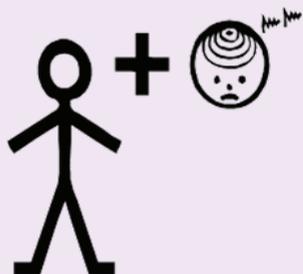
Seizures can also affect the brains influence on the heart and breathing. Research is advancing in the field of SUDEP and is attempting to identify clinical risk factors.

Risk Factors

- Poor seizure control
- Having generalised tonic clonic seizures
- Number of seizures occurring and duration of seizure
- Nocturnal (night) seizures
- Not taking your medication as prescribed
- Medication changes (abruptly)
- Young adult male
- Having epilepsy for many years
- Unwitnessed seizures
- Status Epilepticus
- Infrequent / no medical review
- Excessive consumption of alcohol

Factors potentially minimising risk

- Taking medication as prescribed
- Optimising seizure control
- Referrals to specialist epilepsy services for those with poor seizure control
- Raised awareness of risks associated with nocturnal seizures and better monitoring of these by use of assistive technology e.g. bed alarm
- Education of those with epilepsy, their families and carers
- Avoiding excessive consumption of alcohol



Helpful Organisations

SUDEP Action
Epilepsy Action
Epilepsy Society
Epilepsy Research UK
Young Epilepsy
Epilepsy Foundation

For further information on The Epilepsy Specialist Nursing Service for people with a Learning Disability and Epilepsy in Hertfordshire contact us on 01442 453017.

Contact us

Our website

Information about adult social care – apply online for meals on wheels or a Blue Badge and make a referral for care services

www.hertfordshire.gov.uk/adults

Hertfordshire Directory

Find national and local community groups, charities, services and activities

www.hertfordshire.gov.uk/directory

HertsHelp

Independent information and advice on local community services and care funding

Telephone: 0300 123 4044

Minicom: 0300 456 2364

Email: info@hertshelp.net



01442 453017

Monday – Friday



9:00 to 5:00

Find out about our learning disability nurses and how we can help with your health at www.hertfordshire.gov.uk/LDmyhealth

Health Professionals can find information on our service and tools available at www.hertfordshire.gov.uk/ldprofessionals

epilepsy.referrals@hertfordshire.gov.uk

For more information about Adult Disability Services contact www.hertfordshire.gov.uk/contact or call HertsHelp on 0300 123 4044 or drop into your local library.

Contact us

For information and advice on how to get care and support

Email:

hertsdirect@hertfordshire.gov.uk

Telephone: 0300 123 4042

Textphone: 0300 123 4041

Calls to **0300** cost no more than a national rate call to a **01** or **02** number.

If you are worried that you or someone you know is at risk

of abuse or neglect Call us on **0300 123 4042** (24 hours a day)

If you need help to understand

Call **0300 123 4042** if you would like help to understand this information or need it in a different format. You can also ask to speak to someone in your own language.

