

The Clive Treacey Safety Checklist

Commissioning safer services for people with epilepsy who have a learning disability and/or autism



Portrait of Clive
(2017)

Clive Treacey was a caring, gentle and kind man. He liked to paint, he enjoyed gardening and listening to music.

He was non-judgmental, optimistic, ambitious and trusting. He deeply cared for his family and would never forget significant dates such as birthdays or family occasions.

Clive also had a learning disability and epilepsy and, at the age of 47, he died suddenly following a seizure and cardiac arrest.

Clive's family fought for answers as to why he had died and, some years later, an independent review into Clive's life was conducted – a review that subsequently highlighted “multiple, systemwide failures in delivering his care and treatment that together placed him at a higher risk of sudden death”. One key area where shortfalls were evident was in relation to the decision-making around how Clive was moved between settings and in relation to ensuring that these settings were appropriately able to provide safe epilepsy-care to protect him from harm.

Clive should not have died that day and his death should have been investigated using epilepsy-related national guidance.

This guidance is part of his legacy to ensure that this doesn't happen to anyone else.

Full review available at: [Clive Treacey Independent Review](#)

**Guidance
Document**

Acknowledgements

This project would not have been possible without the funding and support provided by NHS Midlands. Thanks are also due to the steering group, the project's clinical leads Prof. Mike Kerr and Prof. Rohit Shankar, our experts by experience, Elaine Clarke and Christine Jeans, and all the professionals who lent their expertise through the various focus groups and interviews conducted over the course of the project.

Clive's paintings which are used in this guidance are a part of his legacy. Thanks to Elaine and all of Clive's family for sharing these and photographs of Clive over his life-time.

Contact

For any queries or further information about the Clive Treacey Safety Checklist, please email info@sudep.org or call **01235 772850**

Brean Down Inn
Painted by Clive of a much loved holiday destination (~1990)



Guidance for use

This guidance and accompanying checklist are created for use by commissioners, specialist hospital providers and community care providers in order to provide a framework to support safe and effective epilepsy care for people with epilepsy and a learning disability and/or autism. It is intended for use with adults and those transitioning to adult services though many of the themes around safe and effective epilepsy care will also be applicable to children.

It is recommended that the checklist be completed when an individual is transiting between services, annually, as well as in specific response to a change of circumstances.

Such changes of circumstances might include (non-exhaustively):

1. Change in carer network
2. Change in social environment
3. Change in health provider
4. Change in geographic location
5. Change of health and social needs

The guidance comprises a framework by which both providers and commissioners can work together to ensure that they are tailoring services to the same set of expectations.

It is essential that health and social care work together and take shared responsibility for the care of individuals with epilepsy and a learning disability and/or autism at patient level, clinical level and ICB level. The manner in which this can practically be managed will vary by area but funding disagreements should never stand in the way of, or unreasonably delay, an individual receiving safe epilepsy care. Clarity should be sought both for those co-ordinating an individual's care, as well as for the person themselves.

Introduction

With over 600,000 people living in the UK with epilepsy^[1], epilepsy is one of the most common neurological disorders. Approximately a quarter of people with a learning disability have epilepsy^[2] and epilepsy was one of the most frequently reported long-term health condition for people with a learning disability who died prematurely in England^[3]. Epilepsy has also been reported as being the second most frequently reported preventable cause of death in people with a learning disability^[3] and SUDEP (Sudden Unexpected Death in Epilepsy) risk in people with epilepsy who have an intellectual disability is greater than three times than those with epilepsy who do not have an intellectual disability^[4].

Most people with a learning disability and epilepsy need assistance to elucidate and access services that are appropriate, safe and desirable to them. They also need help in understanding and managing their own risks in relation to their epilepsy.

The Independent Review into the death of Clive Treacey^[5] highlighted the tragic outcome when the system within which a person's care is managed fails to adequately meet these most basic of needs. In summary, the review documented failures in relation to 'unsuitable placements', 'inadequate monitoring' and 'staff lacking training and/or who were otherwise unable to adequately ensure Clive's safety'^[5]. Furthermore, best practice pathology guidelines (Royal College of Pathologists Guidance^[6]) were not followed into the investigation into the death of a person with epilepsy.

Guidance for best practice has been in place since 2004 following a national audit into epilepsy-related deaths in 2002^[7] and are outlined through NICE, Step Together, Royal College of Psychiatrists CR203 & 206 and the ILAE seminar series guidance for both SUDEP and neurodevelopmental conditions.

Commissioners have a responsibility to access placements and to signpost bereaved families to timely support. This guidance has been designed to assist commissioners to achieve safer and effective epilepsy care for people with a learning disability and epilepsy.



Pink Azaleas
Mother's Day gift painted by Clive (Staffordshire, 2010)

Contents

		PAGE
	Checklist Guidance	6
1	Epilepsy risk, Sudden Unexpected Death in Epilepsy (SUDEP) mitigation and emergency response	8
2	Epilepsy-care and monitoring	10
3	Co-development and family and voluntary sector involvement	12
4	Transitioning	14
5	Staff training	16
6	Equipment	18
7	Communications	19
8	Monitoring suitability of placement	20
9	Investigations after a death	21

Checklist Guidance

This document provides the explanation behind the items in the Clive Treacey Safety Checklist (“Checklist”) that has been designed to support commissioners and providers to manage standards of safe and effective epilepsy care for people with learning disabilities and/or autism. This document should be used alongside the Checklist.

Both this document and the Checklist have nine sections, which are:

- 1** Epilepsy risk, Sudden Unexpected Death in Epilepsy (SUDEP) mitigation and emergency response
- 2** Epilepsy-care and monitoring
- 3** Co-development and family and voluntary sector involvement
- 4** Transitioning
- 5** Staff training
- 6** Equipment
- 7** Communications
- 8** Monitoring suitability of placement
- 9** Investigations after a death



Clive
Aged 12 (School photo, 1981)



Single red rose
Painted by Clive (2011)



Clive
Day out to a Fire Station (~2005)

Epilepsy risk, Sudden Unexpected Death in Epilepsy (SUDEP) mitigation and emergency response

People with epilepsy who have a learning disability and/or autism should be supported to be kept safe from harm whilst balancing risk against quality of life desires and aspirations. People can die from epilepsy so it is critical that risk factors that are associated with epilepsy-related death (inc. SUDEP) are monitored and minimized.

The SUDEP and Seizure Safety Checklist and EpsMon are recommended by NHS RightCare epilepsy toolkit, the Learning Disability Mortality Review (LeDeR) programme, Step Together, Royal College of Psychiatrists CR203 & 206 and MMBRACE to support person-centred communication SUDEP risk.

1.1

I have reviewed and up-to-date risk assessments covering aspects of epilepsy safety.

Risk assessments are in place both for general epilepsy risks as well as specific risks related to lifestyle. Risk-assessments are up-to-date, maintained and reviewed over time. Risk-management are undertaken meaningfully in order to enable people to access opportunities safely rather than as a barrier to opportunities. Risk assessments are reviewed at least annually and when circumstances affecting risk change over time. They, non-exhaustively, cover aspects related to:

- Seizure-monitoring
- Seizures during sleep
- Medication adherence and risk
- Home environment (inc. kitchen)
- Bathing and showering
- Hobbies and pastimes
- Driving (if applicable)
- Pregnancy (if applicable)

All stakeholder organisations contribute to bespoke risk assessments. The risk assessment is a dynamic tool which needs to be accessible at all times and ideally within the patient domain. Risk assessment tools which are provided from the different organisations are examined to ensure they are holistic in capturing all key seizure-bio-psycho-social risks and there are pre-specified review periods. Auditing of these arrangements takes place every 2-3 years.

1.2

I have an up-to-date SUDEP Seizure Safety Checklist that is periodically reviewed.

As recommended by NHS Rightcare, people with epilepsy who have a learning disability and/or autism have a SUDEP and Seizure Safety Checklist reviewed periodically with them (and advocates or family members as desired/needed) with corresponding discussions around risk-mitigation and safety. Monitoring of medicines management is embedded within this process and outcomes feed into care-plans and risk-assessments.

These reviews are undertaken annually or at a time of change of residence or a new setting being accessed. All actions implicated by the Checklist are undertaken as necessary.

1.3

Staff who care for me know how to react in an emergency.

Emergency protocols are in place with communication channels to follow in case of emergency. Staff are familiar with these protocols and, connected with basic first aid training and use of rescue medication, all staff working with and for someone with epilepsy know how to react in case of an emergency, whether that be related to an individual's epilepsy or otherwise. All family/care staff have had basic epilepsy training. For those on rescue medication such as midazolam, staff and family are trained in its administration and commissioners ensure training is commissioned in accordance with the Epilepsy Nurses Association (ESNA) guidance.



Clive
Cheddar Gorge (2005/2006)

Further information



General

- › NHS Rightcare Epilepsy Toolkit
- › Homes not Hospitals
- › Epilepsy and Risk
- › Management of Epilepsy in Adults with an Intellectual Disability

1.3

- › Best Practice Guidelines for Administration of Buccal Midazolam

1.4

Any safeguarding concerns I have are responded to appropriately and in a timely manner.

All staff have a responsibility to safeguard people with epilepsy who have a learning disability and/or autism and, as such, are able to recognise and report a safeguarding concern. Examples include:

- Lack of basic epilepsy awareness training
- Medication errors
- Environmental risks of epilepsy – including supervision/baths etc.
- Inadequate protocols for seizure reporting
- Seizure-related harm

Safeguarding concerns are responded to quickly, thoroughly and in a manner that preserves the best interests of involved parties.

The theme of 'Epilepsy-Care and Monitoring' refers to the monitoring of both seizure frequency and typology. It also represents the framework by which any changes affecting epilepsy-related safety can be responded to in a timely manner.

All data collected that is used to monitor epilepsy-safety must be accurate, precise and made available to consultants and those supporting an individual's care to inform decision-making.

2.1

I have seizure charts that are maintained and up-to-date.

There is documented evidence that seizures are being monitored and recorded. Charts detail seizure-frequency, seizure-type (if known), seizure-description and duration of seizures as well as any emergency response if applicable. Clinical instructions on seizure monitoring are followed and any changes in presentation of seizures are documented and medical advice sought.

2.2

I have a regularly maintained and up-to-date person-centred epilepsy care-plan.

There is a documented, up-to-date epilepsy care-plan that is in use and updated as and when required. The care-plan covers both the person's epilepsy (including seizure types they experience and medication safety) and other needs, including, but not limited to, employment, education, hobbies, interests, routines and health needs.

2.3

My medication is monitored and reviewed for effectiveness and side-effects with me.

There is evidence of periodic medication reviews with a GP as part of annual health-checks as well as additional reviews in response to change in seizure-manifestation or possible side-effects. At a minimum, these reviews should be undertaken annually with biannual reviews undertaken with an ESN and additional reviews after any period of hospitalization. Time-frames for this need to be tailored to each person and may vary over time depending on their epilepsy, overall health and wellbeing and needs.

People with epilepsy should have the option for the most effective medicine to achieve seizure control. Person-centred communication should be used to support shared decision making about effective treatment and consideration of side-effects especially before any drug is removed or changed.

2.4

My annual health checks are undertaken in a timely manner and findings are addressed.

There are records of annual health checks being undertaken and, as required, consequent follow-up has been actioned within appropriate time-scales.



Clive
Warwick Castle (~2005)

Further information



General

- > NICE Quality Standard Service Improvement Template
- > NHS Rightcare Epilepsy Toolkit
- > Epilepsy Specialist Nurse Competency Framework
- > CQC Fundamental Standards
- > Management of Epilepsy in Adults with an Intellectual Disability
- > NICE - Learning Disabilities and Behaviours that Challenge
- > Purple Toolkit
- > Mencap Health Plan

2.3

- > SUDEP and Seizure Safety Checklist

2.4

- > Annual Health Checks

3

Co-development and family and voluntary sector involvement

The theme of 'Co-development and family and voluntary sector involvement' refers to the engagement a person with epilepsy and a learning disability and/or autism (and/or their families/carers) are empowered to have on the care and support received. Individuals need to be provided with the

information they need and in a form suited for them in order to have meaningful involvement. In cases where they are unable to do so, or where indicated as preferential by the individual, advocacy routes involving family representatives or other advocates need to be enabled.

3.1

I'm involved in co-development of services that I use.

The person with epilepsy and a learning disability and/or autism is actively consulted on the services and treatment that is accessed and received. With the consent of the person with epilepsy, families are actively consulted with as part of the process.

3.2

My mental capacity assessments are undertaken and specific.

Nuances for assessment of mental capacity for different decision-making requirements and at different times are recognised.

There are issues of mental capacity and deprivation of liberty that occur around epilepsy and its treatment that include: medication and other treatment decisions and the use of devices and other means to reduce SUDEP-risk or bathing observation to reduce drowning. All such assessments are performed with full notation of consent and capacity issues and undertaken by someone qualified to do so, following due process and with periodic review.

3.3

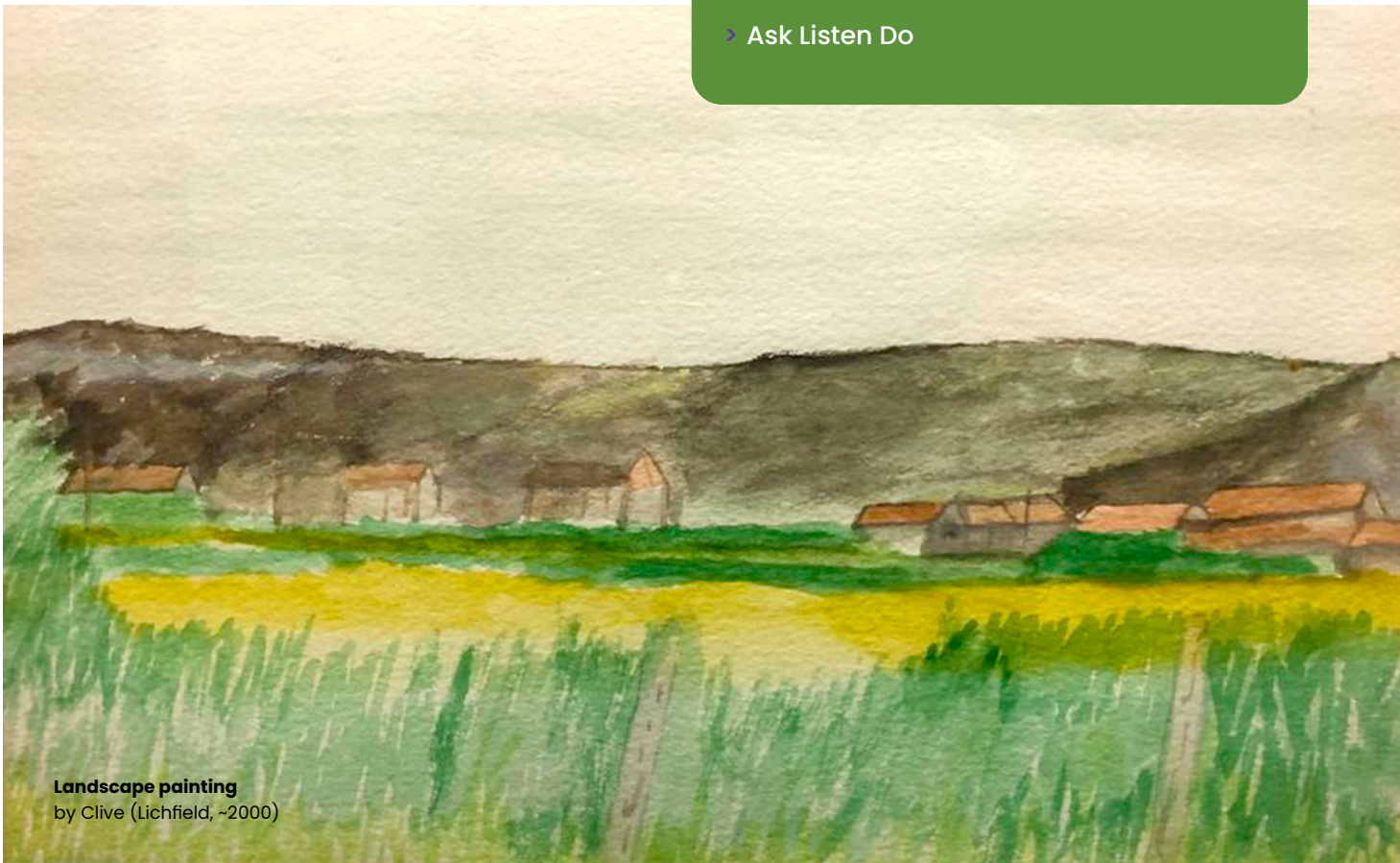
My family members and advocates are involved in epilepsy-related decisions.

Provisions are made to ensure family members (or friends) are involved to the degree that the person with epilepsy and a learning disability and/or autism wishes. Where a person lacks cognitive ability to make informed choices on their care, family members or advocates are involved to make decisions in the person's best interests. Family members are engaged, informed and listened to in order to best meet the needs of the person with epilepsy.

3.4

There is documented evidence that I am meaningfully listened to in relation to my support.

There is documented evidence of meaningfully listening to the person with epilepsy and a learning disability and/or autism to the degree they are capable of and acting upon their wishes. There is evidence (in care plans for example) that they are decision-makers in the care and support they receive. They are supported to access resources to enable them to be informed when making these decisions.



Landscape painting
by Clive (Lichfield, ~2000)

Further information



General

- › Mental Capacity Act 2005
- › EpSMon
- › NHS Rightcare Epilepsy Toolkit

3.3

- › My Life with Epilepsy Risk Information

3.4

- › Ask Listen Do

The theme of 'Transitioning' refers to the process by which information around an individual's care is transferred between different settings. Any change in setting takes into consideration informed

decision-making by the individual themselves or by family or advocacy where lacking ability to do so. Change in settings should take into account a person-centred balance of risk and quality of life.

4.1

My epilepsy care-plan and risk assessments are transferred in advance of transitions.

When transitioning between services or placements, a copy of the person's care-plan and risk assessments is sent in advance in order to enable the service to prepare appropriately.

4.2

My epilepsy risk-assessments are reviewed and updated for before transition occurs.

Existing risk-assessments are reviewed in the context of the change of environment and new risk assessments are created, as required, for any new risks involved during and after transition. This takes into account epilepsy mortality/SUDEP risks which should be reviewed pre- and post-transition.

Any equipment (such as audio or video surveillance monitors) used to manage risk is in an operable state at point of transfer.

4.3

The durations of transitions are agreed and clear upon outset.

Planned durations of stays in new settings are agreed in advance with clear time-scales for monitoring of setting-suitability determined prior to the transition. A named contact at the new setting is provided for the person, family members, advocates and health professionals to contact as required.

4.4

I am involved in transition planning in terms of the place and the method of transfer.

The person with epilepsy and a learning disability and/or autism is involved in transition-planning in terms of the place and timing of transfer. Family members and advocates are involved in the process where it is wished by the service user and where the person lacks cognitive ability to partake in this venture. All necessary support-requirements are in place before the transition is finalised.

4 Transitioning (continued)

4.5

A record of my transitions is maintained and clinical epilepsy care is transferred and confirmed.

Any transitions should have been documented and reviewed as part of wider discussions regarding the new setting's suitability. Where a transition occurs, a clear transition of epilepsy care is organised and in no way can an individual have a period of time without epilepsy review because of a move in service. Worsening in seizures or associated mental health or behaviour should prompt further investigation to ensure safety and review current care and seizure-management.

Further information



General

- › Commissioner's Guide to NCEPOD Report
- › Optimal Clinical Pathway: Epilepsy
- › Homes not Hospitals
- › Step Together



Clive
In art room in St. George's (2007-2012)

All staff working with people with epilepsy and a learning disability and/or autism need to be provided with the necessary basic epilepsy training to enable them to provide safe and effective epilepsy-care.

Training needs to be documented, audited and reviewed and must include safeguarding and risk.

5.1

Staff who work with me have undertaken epilepsy training.

Epilepsy training has been undertaken that is based on best practice guidelines (The Epilepsy Nurses Association (ESNA)). Essential and basic epilepsy training has been undertaken by all staff working with people with epilepsy. Training covers the following:

- What epilepsy is and what are the causes
- How a diagnosis is made
- Seizure recognition, observation and description
- Practical guidance on what to do if someone has a seizure and if seizures cluster or enter a prolonged state.
- Treatment options
- Seizure risk and risk-mitigation
- Status epilepticus
- Care planning and recording mechanisms
- Mortality risk (including SUDEP) and specialist support

(adapted from ESNA Carer Competency Checklist)

5.2

Staff who work with me have undertaken training in care and first aid.

This is a basic requirement for all staff working in the sector and is a fundamental standard listed by the CQC. Training is updated periodically to ensure knowledge is up-to-date.

5.3

Staff who care for me are trained and able to use rescue medication appropriately.

Administration of buccal midazolam is essential risk-mitigation for prolonged or clustering seizures that can be administered by professional carers in the community. [The Epilepsy Nurses Association \(ESNA\)](#) has provided best practice guidance for training carers in the use of buccal midazolam.

5.4

Staff who work with me ensure their skill-set is up-to-date and retained.

Providers of support for people with a epilepsy and a learning disability and/ or autism have monitoring methods in place that are undertaken by qualified professionals to ensure that skill-sets and knowledge acquired through training are being retained and applied appropriately in the work-place. This relates both to the review of any training in the context of the working practices of staff members who have participated, as well as in ensuring that new/temporary staff members and agency staff meet the same standards when working with people with epilepsy who have a learning disability and/or autism.

Further information



General

- > NHS Rightcare Epilepsy Toolkit
- > ESNA Competency Checklist
- > Skills for Care
- > CQC Fundamental Standards
- > Purplelight Toolkit

5.3

- > Best Practice Guidelines for Administration of Buccal Midazolam



Clive
Stafford Castle Herb Garden (2009)

The theme of 'equipment' covers the usage of equipment assessed as being beneficial in the support of a person with epilepsy and a learning disability and/or autism. It includes physical aids such as helmets as well as monitoring devices. It is everyone's

duty to ensure that equipment necessary to mitigate risk is provided and maintained and that any equipment used to alert of seizures is included as part of a wider risk-management plan.

6.1

My safety equipment is assessed for suitability and its use is documented and reviewed.

All equipment is assessed by the care provider and its use risk assessed and documented in the care-plan. Where appropriate, staff are trained in appropriate use of equipment.

6.2

My safety equipment is monitored and periodically checked.

The provider ensures systems are in place to inspect relevant equipment and that they are kept in a good state of repair.



7 Communications

This theme refers to channels of communication with the person with epilepsy and a learning disability and/or autism and their advocates or family members. It relates to that ownership taken for the placement

and care someone receives, and the involvement of professionals who support a person with epilepsy and a learning disability and/or autism.

7.1 I have a designated lead person with epilepsy/LD specialism who I see at least annually.

There is an assigned professional who has a lead-role and overall accountability for co-ordinating professional involvement and liaising with the person with epilepsy's family.

7.2 I see an ESN or LD nurse with epilepsy specialism annually and after any hospitalization.

As recommended by NICE, the service user, and their family, has access to a designated specialist nurse to support their epilepsy-care management as required.

Further information



General

- > NHS Rightcare Epilepsy Toolkit
- > Purple Toolkit
- > Epilepsy Specialist Nurse Competency Framework

The theme of 'monitoring suitability of placement' emphasizes the importance of ongoing review and response to a change of circumstances. These changes can both be triggered by a crisis point or by a gradual and not-obvious deterioration in suitability. Assessments should be undertaken to ensure that a setting is continuing to meet the needs of the person with epilepsy and a

learning disability and/or autism. Feedback should be sought from family members and advocates (where required) as well as the person themselves. Where a setting is no longer meeting an individual's needs, response to ensure continuity of safe and effective epilepsy care should be undertaken as a matter of urgency.

8.1

My placements are periodically reviewed for suitability.

People with epilepsy should not go 'off radar' once they have completed a transfer into a new setting. There is a process for periodic review that involves the service user as well as those involved in their care.

8.2

My feedback is sought in monitoring suitability of placement.

The person with epilepsy and a learning disability and/or autism is an active participant in the monitoring of placement-suitability. Family members and/or advocates are involved where assistance to communicate needs is implicated.

Further information



General

- › Homes not Hospitals
- › Purple Toolkit
- › NHS Rightcare Epilepsy Toolkit

8.2

- › Ask Listen Do

Whilst the priority for this guidance is to promote safe epilepsy care and decrease risk of premature death, it is also important that where a death occurs, the experience

and causes of epilepsy-related death are learnt from and help decrease incidence over time.

9.1

An inquest is undertaken where appropriate

Where a death is sudden or its cause is unknown, an inquest is undertaken to ascertain the cause of death. Inquests may also be held where there are questions about what happened leading up to the death, even if the cause is known. Where a death is sudden or suspected to be seizure-related in a person with epilepsy, it is important for the family and the public interest that the death is investigated using national pathology guidance provided by the [Royal College of Pathology](#) and that learnings from individual deaths are identified and included in a prevention of future deaths report by the coroner.

9.2

The opportunity to learn from a death is given

The [Epilepsy Deaths Register](#) holds data from epilepsy-related deaths over the last 40 years. Professionals and family members have the opportunity to contribute details of a death to help provide answers and help use research to prevent future epilepsy-related deaths. Though not epilepsy-specific, LeDeR should also be informed – which is a service improvement programme

commissioned to improve the standard and quality of care, reduce health inequalities and prevent early deaths for people with a learning disability/autism.

9.3

Timely appropriate support is signposted to for the bereaved.

Those bereaved by epilepsy-related death are provided with the means to access specialist support and counselling by services with expertise in epilepsy-related deaths together with epilepsy specialist casework to answer questions and provide advocacy to help navigate investigations after the death. They have the opportunity to access support to help them through the aftermath of the death of someone close to them ([sudep.org](#)). Sudden unexpected deaths are traumatic. Early intervention by signposting a family to specialist bereavement services can help families access a choice of services for as long as needed. Bereaved people should be given the opportunity for their experiences to inform future practice by submitting to the Epilepsy Deaths Register where there are learnings from deaths. Early intervention with specialist support can enable timely resolution of questions and concerns, can alleviate trauma and benefit both families and professionals.

Further information



General

- > NHS Rightcare Epilepsy Toolkit
- > National Sentinel Clinical Audit of Epilepsy-Related Death

9.1

- > Royal College of Pathologists Guidance

9.2

- > LeDeR
- > Epilepsy Deaths Register

9.3

- > SUDEP Action



Clive
Day trip to farm (2004)

References

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Clive
Christmas (2000)



The Clive Treacey Safety Checklist