

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](#)

Final Report

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.



Clive
Stafford Castle Herb Garden (2009)

Background

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 is the second most frequently reported preventable cause of death in people with a learning disability ^[3]. It is suspected that a significant number of deaths are SUDEP (Sudden Unexpected Death in Epilepsy) - approximately 50% of epilepsy-related deaths are attributed to SUDEP which is where someone with epilepsy dies suddenly and with no other obvious cause (found during post-mortem) ^[4].

Risk factors and SUDEP

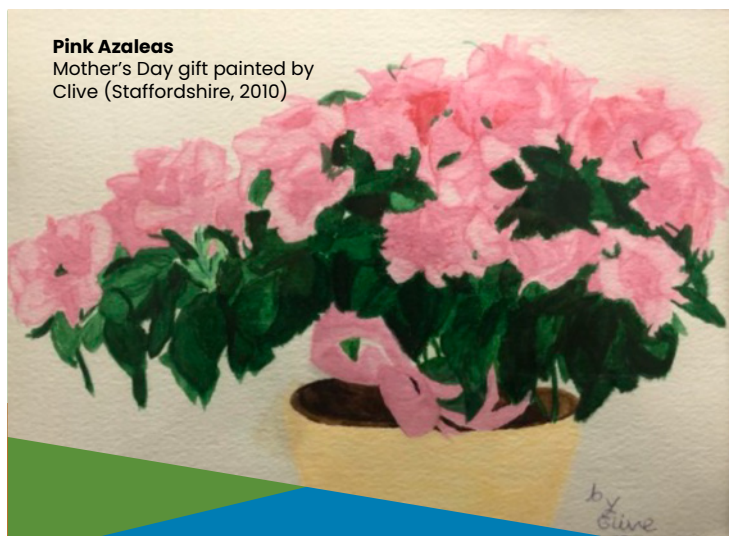
SUDEP risk in people with epilepsy who have a learning disability is greater than three times those with epilepsy who do not have a learning disability ^[5]. Many of the factors that are associated with risk of epilepsy-related death are well-known and, whilst some risk factors are known but unmodifiable (such as male gender, co-morbidities and age at epilepsy onset), many, such as those related to nocturnal seizures, medication-adherence, seizure frequency and control are potentially modifiable ^{[6][7][8][9]}. People with epilepsy, and those supporting and/or caring for them, need support to be able to apply this knowledge appropriately.

People with generalised tonic-clonic seizures have increased risk of SUDEP with research showing SUDEP in them could be prevented if people were not left unattended at night or were free from seizures ^[10]. Recent research has indicated that people with epilepsy and a learning disability who died were less likely to have had a risk assessment than living controls and were less likely to have had an epilepsy review in the 12 months prior to the death. Indeed, reviews within the year potentially reduces risk of premature mortality by 84% ^[11].

People with a learning disability have a variety of needs based on level of cognitive impairment and/or age. People with a learning disability have a greater likelihood of mental health problems and are vulnerable to polypharmacy. Around a third of people with a learning disability have co-morbid neurodevelopmental disorders and

a fifth recognised to have genetic disorders ^[12]. Older adults with a learning disability and epilepsy (defined >40) have a significantly higher level of co-morbid health conditions and mental health conditions whilst having a noted increase in prescribing and lower likelihood of having an epilepsy care-plan in place ^[13].

Many people with a learning disability and epilepsy need assistance to understand and manage their own risk in relation to their epilepsy and to access services that are both safe and desirable to them. However, a recent study in a North London community service reported that over a third of service users with a learning disability and epilepsy who were attending a specialist learning disability service did not have an epilepsy care plan and none had any awareness of SUDEP despite them being part of a higher risk group ^[14]. Recent research still indicates that there is a training needs gap of epilepsy awareness in health and social care professionals ^{[15] [16]}. This, in spite of national guidance in place since 2004 following a national audit into epilepsy-related deaths in 2002 ^[17].



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

The Clive Treacey Review

The Independent Review into the death of Clive Treacey highlighted the tragic outcome when the system within which a person's epilepsy-care is managed fails to adequately meet their needs. The review reported that "Clive's epilepsy care overall fell far short of acceptable practice" and at his final placement he was placed at "higher risk of sudden death".

Over the course of Clive's life, he was constantly moved from setting-to-setting even in cases where his needs appeared to be being met. During this time, both Clive and his family's wishes were often ignored and he got a reputation for being 'challenging', being detained under the Mental Health Act for more than a decade. In addition, on the night Clive died, his CPAP (Continuous Positive Airway Pressure) machine was not functioning and the emergency response was reported as being 'confused and chaotic' ^[18]. 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' ^[18]. These failings continued even after the death as Clive's death was not investigated using best practice pathology guidelines ^[19].

Commissioning and Project Goals

Fundamentally, in Clive's case, there was an evidenced shortage of the required resources for decision-makers to be able to ensure that safe and effective epilepsy care was integrated and maintained within settings and in transitions between settings. Commissioners have a significant responsibility in finding and accessing appropriate placements for people like Clive. It is important to ensure they are equipped with the knowledge about epilepsy to make decisions based on each individual.

The goal of this project was to help address the gaps in safe epilepsy-care evidenced by the report into the death of Clive Treacey. 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. This project was developed to produce guidance for commissioners to better equip them to be able to achieve safer and more effective epilepsy care. This guidance tackles the gap in knowledge and can assist as part of a systemic strategy and action plan to include improvements for epilepsy and learning disability and/or autism.

The approach for this project followed two phases:

2.1

Literature review and expert engagement

A literature review was undertaken using the Treacey review as a starting point to develop a list of themes that constitute 'good epilepsy care for people with a learning disability and/or autism'. In this way, the shortcomings in relation to Clive Treacey's care were cross-referenced against exemplars of best practice including key documents such as 'Step Together' ^[20] the LeDeR mortality review ^[3] and NHS Rightcare's Epilepsy Toolkit ^[21]. The 16 themes that came out of this piece of work were subsequently discussed and amended by a steering group of experts that included both professionals and people with lived experience of supporting a family member with epilepsy in order to merge related themes and maintain distinction between the themes in the final list.

This exercise resulted in a final list of 9 themes being developed:

- 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

2.2

Focus groups and interviews with providers and commissioners

Three focus groups were undertaken with a cohort of 42 people from across the midlands that included commissioners, heads of service, epilepsy specialist nurses, residential providers and quality officers, amongst others. These focus groups targeted the following key areas.

- **Challenges** – What are the current challenges in commissioning and/or monitoring safe and effective care for people with a learning disability and epilepsy?
- **Scope** – In relation to the themes identified in 2.1, will guidance to address these themes be sufficient? Do the themes need to be refined or edited in any way?
- **Guidance** – What should the guidance aim to achieve, how should it look, and how could it best be meaningfully integrated into existing systems?



Clive
Aged 12 (School photo, 1981)

The discussion and insight provided through the focus groups helped to amend and re-construct the pre-existing themes for inclusion in the guidance and ensured comprehensiveness of scope to meeting the goals of the project.

Furthermore, they helped to shape the form of the guidance with a clear preference for a resource that was accessible, person-centred, non-jargonistic and usable by a lot of different people with different specialisms, able to be linked to existing systems and with a clear design for self-assessment.

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

The emergency response by staff on the night Clive died was limited, confused and chaotic and may further have reduced his chances of survival. (p.76)

Lack of risk-awareness around Clive's epilepsy-safety and safeguarding issues were hugely concerning findings in the Treacey Review. Risks of epilepsy-related death were not considered and minimized in the events leading up to his death and emergency response on the night of Clive's death was confused. This theme covers emergency-response and the minimization of risk of epilepsy-death (including Sudden

Unexpected Death in Epilepsy) alongside awareness of related risk-factors. It also refers to safeguarding and the need for concerns to be followed up in a timely and impartial manner. People with epilepsy who have a learning disability and/or autism should be supported to be able to live safely whilst balancing risk against quality of life needs. Any risk factors associated with premature epilepsy-related death (inc. SUDEP) need to be monitored and minimized.

Sub-theme requirements for commissioning checklist:

- Risk assessments are maintained and up-to-date. These cover general epilepsy risks as well as risks related to lifestyle. Non-exhaustively, they cover aspects related to seizure-monitoring, seizures during sleep, medication adherence and home environment (inc. bathing).
- An up-to-date SUDEP & Seizure Safety Checklist is maintained and periodically reviewed. These reviews are taken annually or at a time of change of residence or new setting being accessed.
- Emergency protocols are in place and staff can evidence knowledge of how to react in an emergency. For those on rescue medication such as midazolam, staff and family are trained in its administration in accordance with ESNA guidance.
- Safeguarding concerns are responded to appropriately and in a timely manner.

3.2 Epilepsy-care and monitoring

“ The quality of Clive's epilepsy care-plan, and importantly, its implementation, was inadequate. (p.27)

”

The theme of 'epilepsy-care and monitoring' refers to the capability within the system of care to keep the individual safe, to promote good quality of life and to have the method of management responsive to change. It refers to monitoring of seizure frequency and type. It also represents a means of monitoring any changes that can influence epilepsy-related safety and timely response.

Sub-theme requirements for commissioning checklist:

- There is documented evidence that seizure charts are maintained and up-to-date. Charts detail seizure frequency, seizure-type (if known), seizure-description and duration of seizures as well as any emergency response if applicable.
- There is a documented epilepsy care-plan that is up-to-date and in use. It covers the person's epilepsy and other needs, including, but not limited to, employment, education, hobbies, interests, routines and health needs.
- Medication reviews are undertaken 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.



3.3

Co-development and family and voluntary sector involvement



Clive and his family were not listened to and opportunities were missed to listen to Clive and engage with his family on how best to meet his needs. (p.63)



This theme involves communicating with and listening to the person with epilepsy. It represents an understanding of mental capacity of the individual themselves and of the variability in how that can be expressed both situationally and over time. Co-development at an individual level and in the broader context of available services is key in supporting and empowering people with a learning disability and epilepsy to make decisions and choices around their own life. Family members should be recognised, listened to, and involved, as advocates for the best interests where the service-user is unable to for themselves.

Sub-theme requirements for commissioning checklist:

- The person with epilepsy and a learning disability and/or autism is actively consulted on the services and treatment being accessed and received.
- Mental capacity assessments are undertaken and consider the individual's capacity in relation to the specific need
- Family members and advocates are involved to the degree that the person with epilepsy and a learning disability and/or autism wishes or needs.

3.4

Transitioning



There was a feeling of urgency to move Clive as a result of concerns that St Andrew's Hospital was inappropriate for his support needs. This, combined with the limited options available, meant that the process to find an appropriate interim placement was challenging, and the transition to Cedar Vale was rushed. (p.50)



There were significant issues with Clive Treacey's Review in terms of document-transfer between settings and ensuring that those looking after Clive had the necessary information they would need when they needed it. Communications between teams involved in a service-users care are key here but this theme also focuses on the transition of understanding of needs and knowledge across settings whilst incorporating suitable scrutiny both of assessment and suitability of placement over time. Also included, are preparatory aspects such as risk-assessments (including review of epilepsy mortality and SUDEP risks), advance planning for duration of stay and monitoring.

Sub-theme requirements for commissioning checklist:

- Care-plans and risk assessments are transferred in advance.
- Risk assessments are reviewed and updated before transition.
- Planned durations of stays are agreed in advance with time-scales for monitoring continued setting suitability.
- The person with epilepsy and a learning disability and/or autism is involved in transition-planning.

3.5 Staff training

The level of training and awareness of epilepsy amongst care staff was sometimes very limited and they were not sufficiently equipped to manage complex and drug-resistant epilepsy.
(p.85)

Necessary epilepsy training following The Epilepsy Nurses Association (ESNA) guidance needs to have been undertaken by all staff working with a person with epilepsy and a learning disability and/or autism in order to enable them to provide safe and effective epilepsy-care. This training needs to be in place both by temporary and permanent staff and the applied knowledge of this training needs to be monitored for retention. All training needs to be updated on a regular basis.

Sub-theme requirements for commissioning checklist:

- Staff have undertaken epilepsy training that is based on best practice guidelines provided by ESNA's Carer Checklist.
- Staff have undertaken essential training and first aid. Training is updated periodically.
- Staff are able to use rescue medication appropriately.
- Providers of support for people with epilepsy and a learning disability and or autism have monitoring methods in place to ensure skill-sets are retained and being applied appropriately.

3.6 Availability and maintenance of equipment

Clive's CPAP (continuous positive airway pressure) machine was left in disrepair for at least seven weeks prior to Clive's death and may have been a contributory factor in increased seizures. It was not clear who had overall responsibility for its replacement or how this was to be organised. (p.87)

Staff need the equipment to do their job effectively and well-maintained equipment is necessary in providing good care and managing risk. Any equipment used to alert to seizures are included as part of a wider risk-management plan.

Sub-theme requirements for commissioning checklist:

- Equipment is assessed for suitability and its use is documented and reviewed.
- Equipment is monitored and periodically checked to ensure they are kept in a good state of repair.

3.7 Communications

“ A review of Clive’s medication and treatment by an expert pharmacist suggests that it was not always clear who was responsible for overseeing and monitoring Clive’s epilepsy treatment and care on a day-to-day basis. (p.25) **”**

This theme refers to the involvement of professionals who support a person with epilepsy and a learning disability and/or autism. It relates to the overall ownership taken for the placement and care someone receives and the communication with advocates and/or family members.

Sub-theme requirements for commissioning checklist:

- There is a designated lead professional who has overall accountability for co-ordinating professional involvement and liaising with the person with epilepsy’s family.
- As recommended by NICE, the service user, and their family, has access to a designated specialist nurse to support their epilepsy-care management with reviews undertaken as required.

3.8 Monitoring suitability of placement

“ Commissioning organizations responsible for commissioning and monitoring Clive’s care did not place him in settings that could meet his needs, did not sufficiently monitor the quality of care he received and, on some occasions, this placed him at risk of harm. (p.45) **”**

This theme refers to ongoing monitoring of appropriateness to ensure that the setting is continuing to meet needs for the person with epilepsy. Primary care, annual health-checks need to be being conducted, care-plans need to be adapted as evolving documents and epilepsy risk-assessments need to be updated in response to circumstances and individual needs over time. Feedback should be sought from family members and advocates (where required) as well as the person themselves. Fundamentally, timely discharges also need to be in place where appropriate.

Sub-theme requirements for commissioning checklist:

- Placements are periodically reviewed for suitability.
- Feedback is sought from the person with epilepsy and/or family members or advocates as desired or needed.

Landscape painting
by Clive (Lichfield, ~2000)



3.9

Investigations after a death and support pathways



The series of investigations and complaints handling that took place after Clive's death were inadequate and may have resulted in missed opportunities to take action to prevent harm to others. (p77)



Whilst goals from this project are to minimize risk and provide guidance to support effective commissioning for people with learning disabilities and epilepsy, it is also important to address what happens when someone dies suddenly. The impact of an epilepsy-related death extends far beyond the person, to family, friends and organisations providing the necessary support. It is crucial that those bereaved by epilepsy-related death are supported by specialist bereavement support and that the necessary process is undertaken through investigations such that meaningful learnings can be drawn to prevent avoidable epilepsy-related deaths in the future.

Sub-theme requirements for commissioning checklist:

- Where a death in someone with epilepsy is sudden or its cause is unknown, an inquest is undertaken using best practice national pathology guidance provided by The Royal College of Pathology.
- The opportunity to learn from a death is given by providing the opportunity to contribute to the Epilepsy Deaths Register.
- Support is provided to the bereaved by provision of access to specialist support and counselling 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.

Clive
Warwick Castle (~2005)



4.1

Resources

The form by which the checklist and guidance should be implemented was, again, informed by focus group feedback and the checklist was created in order to meet requirements that the guidance be 'concise', 'easily accessible' and 'with links to other resources'. In order to enable transparency between providers and commissioners, the guidance for each has been matched to ensure compatibility.

The checklist was created to provide a means of monitoring the degree to which a person with a learning disability and epilepsy's care is being managed both safely and effectively. Checklist contents is sub-divided by theme and provides a page reference so that commissioners and providers are working in tandem and, with transparency, towards the same set of expectations.

The guidance was provided separately and with two goals in mind:

For care providers, to help them feel that they can provide better support for people with a learning disability and epilepsy without being clinical experts. For commissioners, to help them feel informed enough to make decisions based on evidence. The guidance provides a reference point for further information on the checklist contents and

provides additional links for background information and resources to support checklist-usage. Using the checklist should give insights into areas of support that are being met and those that might not be being met and can be worked towards. There is space at the end for developing an action-plan based upon checklist completion.

4.2 Limitations

The complexity in relation to many of the challenges being faced are unsurprisingly far-reaching and there is no quick-fix. Participants in focus groups reported that many challenges being faced by those working with and for people with a learning disability and epilepsy were ingrained within layered systems, staffing issues (retention and specialism), high workloads, funding ambiguities, and lack of clarity in relation to roles and responsibilities. Against this backdrop, and with the inevitable variability by area, it is possible that some aspects of the guidance will appear challenging within existing systems. Nonetheless, it is intended that it provide an aspirational target that may be reached in the future within the context of the larger scale changes in relation to managing safe and effective care for people with epilepsy and a learning disability and/or autism.



Brean Down Inn

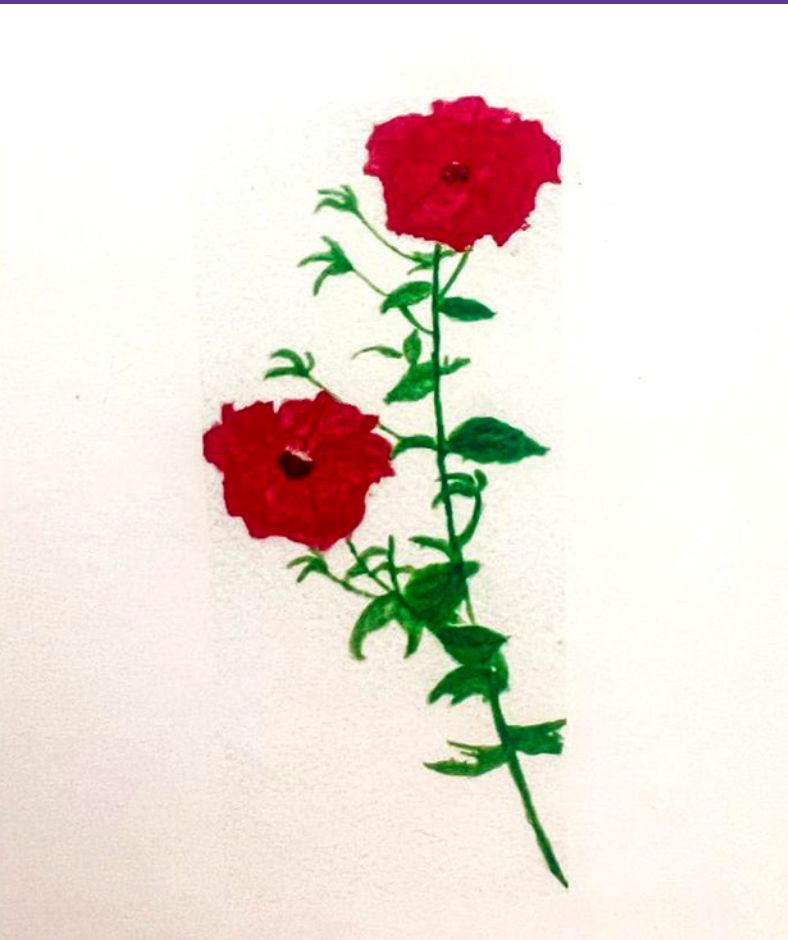
Painted by Clive of a much loved holiday destination (~1990)

4.3 Conclusion

Clive Treacey's review shone a light on a person who was consistently let down by systems that should have been acting in his best interests. It is the intent, and hope, that regular use of the Checklist and accompanying Guidance will help improve person-centred care, quality of life and, most importantly, safety from harm towards the greater goal of preventing avoidable epilepsy-deaths.



Clive
Day trip to farm (2004)



Single red rose
Painted by Clive (2011)



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

- [1] Wigglesworth, S., Neligan, A., Dickson, JM., Yelland, E., Anjuman, T., & Reuber, M. (2023); The incidence and prevalence of epilepsy in the United Kingdom 2013–2018: A retrospective cohort study of UK primary care data. *Seizure*. Vol.105. p37–42.
- [2] Robertson, J., Hatton, C., Emerson, E., & Baines, S. (2015); Prevalence of epilepsy among people with intellectual disabilities: A systematic review. *Seizure*. Vol.29. p46.62.
- [3] LeDeR (2021). Learning Disability Mortality Review (LeDeR), Annual Report, 2020.
- [4] Nashef, L., So, E.L., Ryvlin, P. and Tomson, T. (2012); Unifying the definitions of sudden unexpected death in epilepsy. *Epilepsia*. Vol.53: p227–233.
- [5] Young, C., Shankar, R., Palmer, J., Craig, J., Hargreaves, C., McLean, B., Cox, D., & Hillier, R. (2015); Does intellectual disability increase sudden unexpected death in epilepsy (SUDEP) risk? *Seizure*. Vol.25. p112–116.
- [6] Chen S, Joodi G, Devinsky O, Sadaf MI, Pursell IW, Simpson RJ Jr. (2018); Under reporting of sudden unexpected death in epilepsy. *Epileptic Disord*. Aug 1;20(4):270.
- [7] Faught E, Duh MS, Weiner JR, Guerin A, Cunnington MC. (2008); Nonadherence to antiepileptic drugs and increased mortality: findings from the RANSOM study. *Neurology*. 71(20); p1572–1578.
- [8] Ridsdale L, Charlton J, Ashworth M, Richardson MP, Gulliford MC. (2011); Epilepsy mortality and risk factors for death in epilepsy: a population-based study. *Br J Gen Pract*. 61(586). p271–278.
- [9] Asadi-Pooya AA, Nikseresht A, Yaghoubi E, Nei M. (2012); Physical injuries in patients with epilepsy and their associated risk factors. *Seizure*. 21(3). p165–8.
- [10] Sveinsson O, Andersson T, Mattsson P, Carlsson S & Tomson T. (2020); Clinical risk factors in SUDEP: A nationwide population-based case-control study. *Neurology*. Jan28;94(4). p419–e429.
- [11] Sun, J., Watkins, L., Henley, W., et al. (2023); Mortality risk in adults with intellectual disabilities and epilepsy: an England and Wales case-control study. *Journal of Neurology*. 270. p3527–3536.

- [12] Sun, J. J., Perera, B., Henley, W., et al. (2022); Epilepsy related multimorbidity, polypharmacy and risks in adults with intellectual disabilities: a national study. *Journal of Neurology*. 269(5), p2750–2760.
- [13] Watkins, L. V., Henley, W., Sun, J. J. et al. (2022); Tackling increased risks in older adults with intellectual disability and epilepsy: Data from a national multicentre cohort study. *Seizure*. 101, p15–21.
- [14] Sun J., Perera B., Henley W., Ashby S. & Shankar, R. (2020); Seizure and Sudden Unexpected Death in Epilepsy (SUDEP) characteristics in an urban UK intellectual disability service. *Seizure*. Aug;80. p18–23.
- [15] Lines, G., Henley, W., Winterhalder, R., & Shankar, R. (2018); Awareness, attitudes, skills and training needs of psychiatrists working with adults with intellectual disability in managing epilepsy. *Seizure*. 63. p105–112.
- [16] Gabrielsson, A., Tromans, S., Newman, H. N. et al (2023); Awareness of social care needs in people with epilepsy and intellectual disability. *Epilepsy & Behavior*. Vol. 145. 109296
- [17] Hanna J, Black M, Sander JW, Smithson WH, Appleton R, Brown S and Fish D. (2002); National Sentinel clinical audit of epilepsy-related death: Epilepsy-death in the shadows. *The Stationary Office*; 2002:9–104
- [18] Clive Treacey Independent Review. 2021.
- [19] The Royal College of Pathologists. Guidelines on autopsy practice: Deaths in patients with epilepsy including sudden deaths. July 2019.
- [20] Shankar, R. & Mitchell, S. (2020); Step Together; Integrating care for people with epilepsy and a learning disability.
- [21] NHS Rightcare. Epilepsy Toolkit; Optimising a system for people living with epilepsy. 2020



The Clive Treacey Safety Checklist