



**Clive Treacey**  
Independent Review

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# 1 Foreword

## Beverley Dawkins OBE, Independent Chair

**At the centre of this story is a man who was lost and died in a system that should have become obsolete many years ago. His voice was not heard among the many hundreds of other voices and the lives of people like Clive who seem to their families to count for very little indeed. Throughout his life, Clive's family fought for him every step of the way. They did anything and everything they could to protect him, to challenge what was happening to him and to try to help him achieve his dreams.**

Following Clive's death on 31 January 2017, his family continued to fight, for answers as to why he had died, to get an inquest and eventually for this independent review, to take place some three years later. I would like to acknowledge the directors in NHS England and Improvement (NHSE/I) Midlands who listened to Clive's sister and commissioned this review for their unfaltering commitment to conducting it with honesty and integrity. This review has also benefited immensely from the expertise of Hafsha Ali, the dedicated consultant assigned to this review who has co-written this report.

However, Clive's family should not have had to wait so long for their questions and concerns to be taken seriously. This meant that they were left with unanswered questions, and with the feelings of guilt that maybe there was something else they could have done to save Clive. This has caused them immeasurable harm, but they have carried on fighting for answers because of their firm desire to challenge what happened to Clive and, just as importantly, to help change the future for others. I would like to thank Clive's family, especially his sister Elaine, for sharing Clive's story and working with us to ensure that this review has been conducted and written in a way that places Clive and his family at its heart. Their knowledge and insight into the events that led up to his death have been invaluable. It is my sincere hope that this review shows that families and professionals can work together to seek truth and change.

One of the most striking things about Clive's story is the shocking lack of ambition that professionals and services held for him. Even at the young age of 16, his college tutor notes that 'his hopes for the future are unrealistic'. Clive's hopes for the future were ones that he repeated often to his family and to anyone else who would listen. Clive wanted to have his own home, a ground floor flat or bungalow near his family, a cat, a garden, to go on holiday to Blackpool, to go on holiday with his Mum to Brean in Somerset where he had spent many childhood holidays, to be able to do his photography, art and gardening, and to work in a garden centre helping to grow plants.

That is not what happened to Clive. For those of us who spend our professional lives in the service of people with a learning disability, or are tasked to transform their care, his story will be horrifyingly familiar. We will say that we are shocked but not surprised to hear of another life prematurely lost. We will recognise the same fatal flaws in a system that has been responsible for many other deaths. Indeed, the recently published adult safeguarding review of the deaths of Joanna, Jon and Ben at Cawston Park Private Hospital<sup>1</sup> sharply echoes many of the findings in this review. It was a system that failed Clive and that undermined the efforts of even those who did try to create a better future for him. There really are no words to describe the devastating consequences for Clive and his family and their experience of a broken system that literally swept him away.

<sup>1</sup> Norfolk 'Safeguarding Adults Review: Joanna, Jon and Ben' (2021)

You should read this report because Clive matters. His story is not easy to hear, but his legacy should be that he turns the anger, distress and frustration you will feel when you read about what happened to him, into action to stop other people from dying and to live a life that is worth living. Clive and his family deserve nothing less.



*A portrait of Clive.*

## NHS England and Improvement - Midlands

**Clive Treacey was young at only 47 at the time he died. We commissioned this independent review to understand Clive's journey during his lifetime and to review the care he received. We wanted to show how Clive's life mattered and the lessons that could be learned from his and his family's experience.**

We would like to thank Beverly Dawkins for undertaking this review and Hafsha Ali for the support she gave to Beverley to produce this final report. We thank Jacqueline Barnes, Director of Nursing in the Midlands nursing team for her tenacity in supporting Beverley and Hafsha and her liaison with Clive's family to keep them informed of progress. We also are appreciative for support received from the National Learning Disability and Autism programme, in particular Sue North who provided advice and guidance to the recommendations.

Thanks are extended to the organisations involved for their engagement and openness which has resulted in such a comprehensive report. We will continue to work closely with the organisations to support them in the delivery of the recommendations so that people with a learning disability, autism or both and their families experience the care and support they need and deserve.

Finally, our sincere thanks to Clive's Family for bringing his experience to our attention, for their positive and welcome challenge to us and the authors, and for sharing their experience so honestly and openly. Without this committed family Clive's story would not have been told and recorded in this report.

**Jeff Worrall, Regional Director for Performance & Improvement and Regional lead for Learning Disabilities and Autism, Midlands – NHS England and Improvement**

**Siobhan Heafield, Regional Chief Nurse, Midlands – NHS England and Improvement**



## 2 Introduction

**Clive died on 31 January 2017 following a seizure and cardiac arrest from which he did not recover. His family have fought hard for the answers to their many questions about why he died, how it was that he spent so many years detained in specialist hospitals, why he was not kept safe from harm and why he did not get to live the life he and his family hoped for. His family have raised many questions about the events that led up to his death, remaining dissatisfied with the outcome of the investigations and the inquest that followed.**

In July 2020, NHS England and Improvement (NHSE/I) Midlands commissioned an independent review in line with the principles of the Learning Disability Mortality Review (LeDeR) programme methodology, into the serious matters raised by Clive's family about his experience of care and the circumstances leading up to his death.

The LeDeR programme, established in 2017, aims to drive improvement in the quality of health and social care service delivery for people with a learning disability. It does this by looking at why people with a learning disability typically die much earlier than average and by reviewing the deaths of people with a learning disability.

The objectives of this independent review, applying the principles of LeDeR, as cited in the terms of reference, were to:

- Establish a clear and factual picture of Clive, his health and wider support needs, and the extent to which these were met by health and other services.
- Establish a chronological timeline of Clive's life and the circumstances that led up to his death.
- Identify any potentially avoidable factors that may have contributed to Clive's death.
- Assess whether Clive's death was potentially avoidable (potentially avoidable deaths are those where there are aspects of care or support that, had they been identified and addressed, may have changed the outcome and on balance of probability the person may have lived for another year or more).
- Establish any learning for the health and care system around the circumstances of Clive's death and care leading up to his death.
- Identify any areas of good practice in relation to the care and support of Clive prior to his death.
- Where learning is identified, develop appropriate recommendations and action to improve the quality of health and care provision and reduce premature death.

The agreed terms of reference identified that issues may emerge in the course of this work that fall outside of the remit of this review and that require further investigation. This has been the case and, as agreed, consideration has been given to the nature of further investigations required, which are included in the final recommendations of the review.

## 3 Methodology

**This independent review has applied the nationally prescribed methodology for LeDeR reviews. It is distinct from the usual LeDeR process, as deaths subject to LeDeR review do not usually require the commissioning of an independent review. The reason why an independent review was commissioned in relation to Clive is due to the exceptional circumstances of the case and the serious matters raised by Clive's family about his experience of care and the circumstances leading up to his death.**

Commissioned as an independent review by NHSE/I Midlands, this work has been led by an Independent Chair appointed in consultation with the family and supported by a dedicated senior consultant. The review has been overseen at a regional level by NHSE/I Midlands Regional Quality Board.

The family's confidence in the process was critically important. A commitment to conducting an independent and transparent review was embedded in the terms of reference and has remained central to the review throughout. The review team has worked closely with the family through weekly meetings and ensured that they have had sight of all drafts of the report through to its final conclusion.

The review began with several detailed discussions with Clive's sister to establish a comprehensive understanding of Clive, his journey and the family's experience. These discussions have been recorded and form part of the information record.

An extensive body of care records and information from a wide range of sources dating back to as early as 1987 have been collated and analysed to establish a holistic picture of Clive's journey. Most organisations positively supported this process, providing records and information held. In some cases, the information and records available were very limited or not available at all. In conducting this review we have, in a number of cases, had to rely on the evidence and records retained by the family, rather than this having been despatched to us in an open and transparent manner by the organisations involved and in line with the obligations set out in the 'Duty of Candour'<sup>2</sup>. As far as possible, evidence and information has been triangulated from different sources to test its validity.

Interviews have been held with a mix of professionals involved in the last year of Clive's care including care providers, commissioners, and Clive's specialist epilepsy consultant. Evidence and findings of significant investigations into Clive's death such as the Coroner's inquest, serious incident reviews, Care Quality Commission (CQC) investigations and a safeguarding review have been examined.

The review is informed by the professional expertise of appointed experts who reviewed Clive's care records and provided independent specialist advice on key issues arising from this review. The experts formed a panel to collectively review the complete findings and determine whether Clive's death was potentially avoidable. The following experts were engaged in this review: a cardiologist, an advanced clinical nurse specialist in epilepsy, an independent pharmacy consultant, a Mental Health Act (MHA) consultant nurse-approved clinician, and a consultant with experience of health and social care commissioning for people with a learning disability. Advice was also sought from several specialist national bodies.

The final report has been validated by factual accuracy checks with organisations referenced in the report, two legal reviews and a process of stakeholder engagement.

<sup>2</sup> [UK Government guidance: 'Duty of candour' \(2020\)](#)

## 4 Pen portrait: Clive

The death of Clive Treacey, at the age of just 47, left a gaping hole in the lives of his very close family. A very much loved son, brother, cousin, uncle and great-uncle, he left a trail of wonderful memories behind him, captured in the photographs he took himself of many happy family times, together with painstakingly made matchstick models of cathedrals and the Eiffel Tower. 'His artistic work has won many competitions and hangs in all our family's homes. With his beautiful creations he had an ability to capture all our treasured memories.' (Clive's parents).



*Painting by Clive of Brean Down Inn in Brean, a longstanding and much-loved holiday destination for Clive and his family.*

Clive's parents, Pauline and Michael, described what an absolute privilege and honour it was to be Clive's parents. "We are truly blessed by our son Clive's kind, gentle fun-loving spirit, Clive's heart knew no bounds, his magical qualities stayed within Clive his entire lifetime."

Clive loved his family, and his sister Elaine recalls how one day she went to meet him and seeing her at the top of the hill, he ran all the way up shouting her name and showing her so much love that strangers nearby had to stop and smile. His Mum and Dad remembered how whenever his family entered any room Clive would go out of his way to tell everybody and anyone who they were and how proud he was of them. "He never judged us once, he always trusted us both his entire life, he always told us all constantly how much we were all loved and adored as we told him, every time, every single time without fail."



Clive loved writing letters and he constantly wrote to all family members, not once forgetting a single birthday, Easter or Christmas card. "He is known as the family calendar. We all relied on Clive's ability to never forget." They recall how much Clive loved Christmas and sharing all its wonders with the younger members of the family and sometimes complete strangers; how he loved to party, dancing the night away and how he refused to let the party ever end. Clive would constantly burst into laughter and song throughout his lifetime. They felt that Clive's real passion lay within his art and music: "Especially Elvis, and he burst out singing many a tune anywhere and anytime".

Clive cared about other people and he made sure he said hello to everybody he met "with a passing hello or goodbye or 'take care of yourself!'" He took pride in his appearance, polished his boots like his dad, had impeccably good manners, and was generous and kind. He loved to win competitions and prizes – and he usually did. His Mum used to say: "Somebody else has got to have a chance to win, son... yet he still always won." He took on many charity events to assist others, with constant excitement about his achievements and certificates, which he would never allow to be put in a drawer but always on display.

Clive shared his sister Elaine's sense of humour and she recalls how they, like any other brother and sister, used to laugh about inappropriate things together. He valued the simple things in life and was everybody's friend. He was kind, forgiving and 'oozed humanity' (Elaine). Clive was artistic and creative. He was patient and had an eye for detail. He liked to paint, getting the details just right. He loved gardening – he "only had to look at a patch of brown earth and before we knew it, something would grow there – 12ft high!" (Elaine).



*Painting of pink azaleas, flowers Clive bought for his mum on Mother's Day every year.*

Phil, Clive's younger brother, remembers that as children their mum would always knit identical clothing for Clive and himself, and how a parade, painful though it was at times, would always follow – with photographs. These inseparable moments have and always will be remembered by Phil, and also the simple gesture of Clive usually putting his arm around him without prompt. Clive's warm and priceless caring nature continued all his life. He welcomed strangers with no questions or judgement and allowed his honesty and trust of others to be his guide.

Phil recalls that, when their teen years approached and Clive was taken away from them, with each reunion, Clive's deterioration was clear, but that Clive's optimism never left him. When Clive would phone Phil, two topics always came up to start the conversation. Clive would always open with the words "I have some good news, Phil." This news would usually relate to a change in his medication, or his passion for plants. Secondly, he would always ask how Savannah-Sky and Blake (Phil's two children) were. Phil says: "I have to live with the regret that I didn't always give my brother the time that he was always willing to give to me and to others. Two words sum up the start of each conversation led by my loving brother Clive – hope and family."

Clive encountered many other people across his life. Amid the volumes of education, health and care records we have reviewed, as well as some of the people we have spoken to in the course of this review, Clive's personality shines through. Clive loved school and he was determined to go to college like his brother and sister. At college he was described as verbal, assertive, enthusiastic, punctual, consistent, able to concentrate for long periods, not afraid of hard work, very cooperative, having a gentle engaging sense of humour, "an asset to the woodwork department". He was able to read and understand simple texts, had good number concept and was pleasant and cooperative. A psychologist who met him in his last placement remembered him as engaging, humorous, lovely, jokey, a pleasure to work with and a real gentleman.

People also noticed that he did not like loud places and noisy people and if things became too hectic, he would keep himself to himself and opt for more gentle and humorous exchanges with the people he liked best. A learning disability nurse described him as "fun, a comic, a real character who loved to make you smile". She recalled how an 'Olympic games' had been staged at the service and Clive, who was a good runner, had won a medal and refused to take it off for days. She also recalled how Clive had once attended his care review meeting wearing his Homer Simpson slippers, sitting himself down and putting his feet on the table just to make sure everyone had noticed!

Clive's family recalled how he had a clear vision of the life he wanted – to have his own home, a ground floor flat or bungalow near his family, a cat, a garden, to go on holiday to Blackpool, to go on holiday with his Mum to Brean in Somerset where he had spent many childhood holidays, to be able to do his photography, art and gardening, and to work in a garden centre helping to grow plants. He also wanted to learn to drive a car, like his Dad. "Clive was simply Clive; he knew and was encouraged to go grab those dreams all of our children had." (Clive's Dad).

Clive's parents talked about how he was labelled 'a naughty boy' by so many people and their sadness and frustration that so often, 'these people never sat and asked him one single question about the nature of the upsets'. They felt that no one ever understood or accepted that Clive was far more capable than they gave him credit for. They saw that Clive was capable of standing up for himself at times, and that this did cause him many an upset with people who pushed him to his limits. They explained that Clive lived in a very black and white world and that "he knew exactly what was what, and what he wanted to say – and this brought him many a challenge".

Despite all the things that were to happen to Clive in his life, he was 'the master of positivity', often telling Elaine to "forget it now, it's over, today is a new day". Clive's parents said that: "despite all his suffering and what he had to endure, he took everything in his stride, never sought to dwell on things, complain or allow medical challenges to prevent his activities or

dictate his planning. He would instantly brush himself off and carry on regardless, forever positive, never letting anyone or anything stop him reaching his ambitions and goals.” They recalled how, during the very many days and years when he was denied his freedom to participate in a life like that of his brothers and sisters, how he was “driven by such courage and strength to achieve all he wished to be and could so easily have achieved” and how “he point blank refused to let his days of suffering keep him down for long, never once did we hear our child ask or question why?”

Clive’s family say that they knew that he would die in the months and weeks leading up to his death and, sadly, that Clive did too. Earlier in the last evening of his life, Clive packed his bag and rang his sister to say that they were coming for him in the morning. He left a message on his father’s phone, a message that tragically did not reach his dad until some days after his death, saying he was dying and needed an ambulance.

“Clive always walked the walk with pride and we his parents always walked tall with pride beside him. Our hearts will be forever broken and we will spend our lives forever missing our beautiful, kind, gentle, loving son Clive. He was the best of all of us and we are forever proud to say Clive was our son.” (Michael and Pauline, Clive’s parents).

## 5 Summary findings

**Clive was a much-loved family member and a man who had clear aspirations about his adult life: a place to live in the community that was close to family, and a job, ideally in a garden/horticulture setting (see Section 4: Pen portrait). Clive never realised this dream, and like so many of the people we have come to know within the post-Winterbourne<sup>3</sup> programmes, he was caught in a system that could not and did not meet his needs and that lessened his chances of ever finding a place to call home.**

Passed from setting to setting, he ended up being detained under the Mental Health Act (MHA) for a decade. There was a lack of National Institute for Health and Care Excellence (NICE)-compliant good quality care and treatment for his presenting needs, and in some cases, although the minimum standards were met, they were insufficient to meet Clive's needs. He gained a reputation for being complex and challenging, and someone for whom a community setting was not properly considered until the last years of his life. When it was, there were financial and systemic barriers that thwarted these attempts and he remained incarcerated in settings that were poorly equipped to meet his needs, in the last of which he tragically died.

Clive's family supported him at every step along his journey. They fought for Clive, for the life that they knew he wanted and to which he had a fundamental right. They raised their concerns loudly, directly to the services, through complaints and safeguarding processes – but they were rarely listened to. Towards the end of Clive's life, they had a strong sense that he was going to die and still their voices were not heeded. After Clive died, his family had to fight for an inquest and then fight again for this independent review in line with the principles of LeDeR methodology. This condemned them to further trauma and to living with many unanswered questions. Together with the loss of a loved family member, this has also had a profound and detrimental impact on their lives.

This review has considered the physical causes of Clive's tragic death, together with the quality of care he experienced over his lifetime. We have reached our conclusions by listening to the serious concerns raised by Clive's family, conducting a substantial review of Clive's health and care records, listening to the recordings of the Coroner's inquest, interviewing staff involved with Clive's care and by commissioning expert advice and evidence.

**This review finds that Clive's death was 'potentially avoidable'<sup>4</sup>. There were multiple, system-wide failures in delivering his care and treatment that together placed him at a higher risk of sudden death as set out in the report.**

**Clive should not have spent so many years of his life detained in specialist hospitals. There were extensive periods when he experienced an unacceptably poor quality of life and where he was not always kept safe from harm.**

<sup>3</sup> An investigation into the care provided at Winterbourne View Hospital in 2012 found many people with a learning disability or autism and who had mental health conditions or behaviour that challenges received poor quality and inappropriate care. ([Definition source: 'Winterbourne View: Summary of the Government Response'](#))

<sup>4</sup> **Potentially avoidable deaths** are those where there were aspects of care and support which, had they been identified and addressed, may have changed the outcome and on balance of probability the person may have lived for another year.



## Findings

1. The post-mortem<sup>5</sup> and Pathologist's report that followed Clive's death failed to consider epilepsy / SUDEP (Sudden Unexpected Death in Epilepsy) as the cause of death.
2. Clive's epilepsy care overall fell far short of acceptable practice for someone with complex intractable (drug-resistant) epilepsy. At Danshell Cedar Vale (now Cygnet Health Care)<sup>6</sup>, his final placement, this placed him at higher risk of sudden death.
3. Clive experienced health inequalities throughout his life that had a negative impact on his quality of life, some of which caused him pain and suffering for prolonged periods of time and placed him at greater risk of premature death.
4. Commissioning organisations responsible for commissioning and monitoring Clive's care did not always place him in settings that could meet his needs and did not sufficiently monitor the quality of care he received. On some occasions, this placed him at risk of harm.
5. There was a lack of good quality care and treatment for Clive's presenting needs, including NICE-compliant approaches to behaviour analysis and intervention, in the specialist hospitals in which he was detained. For the most part, responsible clinicians overseeing Clive's inpatient care did not see life outside of hospital as an option for Clive and failed to pursue a timely discharge for him. Alongside the impact of institutionalisation, this moved him further away from living the life he wanted and resulted in an unnecessarily prolonged detention in hospital of nearly 10 years.
6. 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.
7. Clive was not always kept safe from harm while in the care of some care providers. The response to the many complaints and safeguarding alerts raised by the family and professionals were inadequate.
8. The safeguarding response to the alleged sexual abuse Clive experienced over several years failed to protect him from further harm and may also have failed to protect others.
9. The emergency response by Cedar Vale staff on the night Clive died was limited, confused and chaotic and may further have reduced his chances of survival.
10. 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.

<sup>5</sup> A **post-mortem**, also known as an autopsy, is the examination of a body to understand the cause of death. They are carried out by specialist doctors called pathologists. ([Definition source: NHS](#))

<sup>6</sup> Danshell Limited owned Cedar Vale for the duration of Clive Treacey's care. However, Cygnet Health Care Limited purchased Danshell Limited on 1 August 2018 and took over the services from this date.

## 6 Timeline

The information in this timeline is drawn from a substantial body of records gathered from many different organisations and sources. While the review has sought to cross-reference information to confirm its accuracy, some of the records reference historical information for which this has not been possible.

Date	Circumstances
13/12/1969	Clive was born on 13 December 1969. He was born by spontaneous normal delivery at nine months gestation. He was cyanosed <sup>7</sup> at birth and was in neonatal intensive care for approximately two weeks. Clive's early developmental motor and sensory milestones were normal, but signs of a learning disability became apparent in infancy.
1969–1977 (early years)	At the age of 2, Clive started to experience a floppiness of the body accompanied by shaking and balance issues. He would experience severe headaches and constant cyclical vomiting. He would experience two good days followed by two or three days in a blackout room, as the sight of daylight would cause him to scream in pain. Clive was seen by his GP at the age of 2 for sleep difficulties and prescribed Phenytoin, an anti-epileptic drug for cyclical vomiting. There was a view that these episodes may have been manifestations of seizures.
1977–1985 (school age)	As Clive grew older these symptoms continued to persist, lengthening in their duration with every year Clive got older. By the age of 8, Clive was presenting regularly to accident and emergency (A&E), and as a result this was investigated by a consultant neurologist and psychiatrist. At this time, Clive was also referred for a brain magnetic resonance imaging (MRI) scan in which a pinhead shadow was detected. Clive's parents were assured that this was nothing to be worried about. The age at which Clive was formally diagnosed with epilepsy is unclear, but records indicate that it was around the age of 8–10 years.
1981 (age 12)	Mainstream schools did not feel able to continue to support Clive due to his epilepsy, and Clive was offered a place at a specialist school for children with physical disabilities.
May 1986 (age 17)	Clive was tentatively diagnosed with Lennox-Gastaut syndrome, a complex type of epilepsy with difficult to control convulsive seizures.
1987–1989 (age 18–19)	As Clive approached 18, there were no colleges locally and regionally open to him due to his epilepsy. Clive moved to Lingfield Hospital School, a specialist residential college for young people with a learning disability and epilepsy in Surrey.
1989–1993 (age 19–23)	Following college, Clive moved to a residential setting in the northwest of England providing education, medical and therapeutic support for people with a learning disability and epilepsy.

<sup>7</sup> **Cyanosis** can mean there's not enough oxygen in your blood, or you have poor blood circulation. It can be caused by a serious problem with the lungs, airways or heart. ([Definition source: NHS](#))

<b>1993 (age 23)</b>	Clive was urgently moved from this setting following a police investigation into alleged sexual abuse of Clive by a member of staff.
<b>March – October 1993 (age 23)</b>	In March 1993, Clive moved to the Sands Centre in Rugby, a small six-bed residential home. The family shared that the provider felt unable to keep Clive safe due to the level of seizure activity and injuries he was sustaining and so he was moved after seven months.
<b>November 1993 – March 1998 (age 23–28)</b>	In November 1993, Clive moved to Richmond Mews, a specialist care home with nursing provision for people with a learning disability in Stoke-on-Trent. While here, Clive received specialist care from the Learning Disabilities Team from Hanley and the behavioural neurosciences unit at Haywood Hospital, Burslem.
<b>31 October 1997 (age 27)</b>	Clive was diagnosed with a brain tumour.
<b>23 February 1998 (age 28)</b>	Clive underwent surgery to remove the brain tumour ('a right temporal subtotal resection of an astrocytoma').
<b>March 1998 – May 2002 (age 28–33)</b>	Clive moved back home in March 1998 to live with his mother in Lichfield. During this time, Clive attended local learning disability day services five days a week and would also regularly access respite services for short periods.
<b>1998–1999 (age 28–29)</b>	In 1998 it was revealed that the perpetrator suspected of alleged sexual abuse in 1993 had continued to access Clive at subsequent placements. A case review involving Lichfield Social Care (Staffordshire County Council) and Lichfield Police (Staffordshire Police) was initiated.
<b>1999 (age 29)</b>	In 1999, Clive was admitted to the Neurology Ward at North Staffordshire Hospital for assessment following significant 'increase in seizures and involuntary jerky movements which often went on for hours and resulted in carpet burns and bruises to his head'. No clear diagnosis was given.
<b>March 2000 (age 29)</b>	In March 2000, Clive was reported to be having 20 seizures or more per morning, and was admitted to Good Hope Hospital in the West Midlands where his epilepsy was stabilised. He was subsequently referred to the Neurology Team at Queen Elizabeth Hospital in Birmingham.
<b>May – July 2000 (age 29)</b>	In May 2000, Clive was informally admitted to the George Bryan Centre for a mental health assessment following an episode of aggression. Clive was transferred from here to the White Lodge Centre Assessment Unit, where he had an inpatient psychiatric assessment, but no formal psychiatric diagnosis was made. Clive was discharged home to the care of the local learning disability team.
<b>August 2000 – August 2001 (age 30–31)</b>	In August 2000, Clive was temporarily moved to Hawthorn House, a large residential home in Staffordshire for people with a learning disability. This was a temporary arrangement while a more permanent solution was sought.

<p><b>August 2001 – early 2002 (age 31–32)</b></p>	<p>In August 2001, a more permanent home was identified for Clive at Avenue Road in Darlaston. This was a five-bedded, small home environment that was jointly funded by South Staffordshire Health Authority (which later became Staffordshire Primary Care Trust) and Staffordshire County Council. Clive’s family shared that the provider was unable to support Clive’s epilepsy and behaviour, and he was subsequently moved.</p>
<p><b>Early to mid-July 2002 (age 32)</b></p>	<p>In early 2002, Clive was temporarily moved to Stretton Edge – a respite unit in Barton. In March 2002, Clive was admitted as an emergency to the psychiatric unit at Stonefield House, St George’s Hospital in Staffordshire for 12 weeks following threatening behaviour. The behavioural deterioration was thought to be secondary to an anti-epileptic drug, Topiramate, which was replaced with another, Gabapentin.</p>
<p><b>Late 2002 – circa 2005/06 (age 32–36)</b></p>	<p>Following the 12-week assessment at the psychiatric unit, Clive was moved to Suttons Drive in Great Barr. This was a small residential home for people with a learning disability offering rehabilitation. Clive lived here with five others and four full-time carers. In 2006, there was a dispute between Staffordshire Primary Care Trust (PCT) and Walsall PCT around the funding of package which fell across commissioning boundaries and the family report that Clive was moved as a result.</p>
<p><b>01/06/2005 – 24/06/2005 (age 35)</b></p>	<p>In June 2005, Clive was referred to the Chalfont, University College London’s National Hospital for Neurology for a 21-hour electroencephalogram (EEG) recording to better understand his epilepsy. This assessment helped to establish the type, frequency, characteristics, and triggers of seizures.</p>
<p><b>2005–2006 (age 36)</b></p>	<p>Around 2005/06, Clive moved to Heritage Care in Burton, a small residential home. Here Clive lived with three other men with complex needs supported by two members of staff. Having moved from a structured environment with lots of support to a small home with more hands-off support, the family shared that Clive could not cope with the lack of structure and support. Clive’s behaviour deteriorated very quickly, and additional support was brought in, but it was felt that Clive could not be supported here, and alternative provision was sought.</p>
<p><b>2006–2007 (age 36–37)</b></p>	<p>In 2006/07, Clive was moved to Burlington Villa – a residential care home in Nottingham that provided specialist support for people with a learning disability, autism and brain injury. The family report that Clive struggled with the behavioural programme applied in this setting, and following a difficult series of events, the provider served notice for Clive to leave.</p>
<p><b>30/07/2007 – 03/07/2012 (age 37–41)</b></p>	<p>On 30 July 2007, Clive was admitted to the Margaret Stanhope Centre where he was detained under Section 3 of the Mental Health Act (1983). He was subsequently transferred to Stonefield House, St George’s Hospital for short-term assessment. Stonefield House was considered in view of ‘his episodic challenging behaviour and the associated risks he posed to others and himself’. In 2011, St George’s Hospital was recognised as no longer being appropriate for Clive, and a long-term placement was sought.</p>



<b>April – May 2011 (age 41)</b>	Clive was interviewed by Staffordshire Police following disclosure to staff about alleged historic sexual abuse.
<b>03/07/2012 – 16/04/2013 (age 42)</b>	In July 2012, Clive was admitted from St George’s Hospital to the Tallis unit at St Andrew’s Hospital in Northampton, detained under Section 3 of the MHA. This is a secure, 14-bed inpatient care and rehabilitation unit for adult men who have an acquired/traumatic brain injury and who experience complex behavioural, psychiatric, and emotional difficulties.
<b>February 2015 (age 45)</b>	Discharge planning to transition Clive out of hospital commenced in 2015 – led by NHS Stafford and Surrounds Clinical Commissioning Group and Staffordshire Transforming Care team.
<b>04/05/2016 (age 46)</b>	Clive was transferred to Cedar Vale in Nottingham, an assessment and treatment unit for men living with a learning disability, autism and complex needs. This was intended to be a short-term interim placement offering rehabilitation support that could meet Clive’s needs with a view to securing a bespoke package in the community in the near future.
<b>31/01/2017 (age 47)</b>	<p>At 04:25, a care worker was alerted to a noise in Clive’s bedroom and attended to find him having a seizure. The care worker checked Clive’s airways to find he was breathing, and the nurse call alarm was initially pressed followed by the emergency alarm.</p> <p>At 04:27, the onsite learning disability nurse arrived. She fully entered the room at 04:30, where she found Clive having a seizure. He was breathing heavily, gasping for breath and his whole body was reported to be moving (there were no initial concerns, as this pattern of recovery was normal for him). The nurse proceeded to take Clive’s oxygen reading which was at 96% and falling. Oxygen was administered at 10l/min, but oxygen saturation continued to fall. Clive was struggling to breathe.</p> <p>At 04:40, Clive’s oxygen levels continued to drop. They reached 90% and East Midlands Ambulance Service was called. The learning disability nurse started chest compressions with Clive on the bed.</p> <p>At 04:48, on the advice of the 999 call handler, a defibrillator was brought in, and Clive was moved from the bed on to the floor. Chest compressions using the defibrillator commenced and were ongoing (with one 30-second pause) until the paramedics arrived. Records suggest that two shocks were given during this time.</p> <p>At 05:06, the paramedics arrived at Clive’s room. On their arrival, there was no heartbeat or breathing sounds, and Clive’s eyes were fixed and dilatated. The paramedics continued to administer advanced life support for a further 20 minutes with no response (Clive was asystole<sup>8</sup> throughout).</p> <p>At 05:27, efforts to resuscitate (CPR) were ceased, and Clive was pronounced dead.</p>

<sup>8</sup> **Asystole**, more often referred to as **flatline**, is when there is no electricity or movement in the heart. This means there is no heartbeat. ([Definition source: WebMD](#))

# 7 Findings

## 1. Cause of death

**The post-mortem and Pathologist's report that followed Clive's death failed to consider epilepsy/SUDEP (Sudden Unexpected Death in Epilepsy) as the cause of death.**

At the outset of this review, Clive's sister explained to us that, in relation to the cause of death, the family had consistently questioned the impact of the severe seizure on Clive's heart on the night that he had died. She explained that this had not had the amount of scrutiny that they believed it required. They were also concerned that Clive had not been investigated for a heart condition that had resulted in some family members dying prematurely when he had been complaining of chest pain over a long period of time.

We have given careful consideration to both of these points, and began by reviewing the evidence set out in the post-mortem, the Pathologist's report and the inquest:

Clive died on 31 January 2017. A post-mortem was carried out on 7 February 2017. The Pathologist's report concluded that Clive died of:

- 1a) Ischemic heart disease<sup>9</sup>
- 1b) Coronary atheroma<sup>10</sup>
- 2) Left ventricular hypertrophy, steatohepatitis<sup>11</sup> and chronic kidney disease.

The Pathologist who was engaged by the Coroner stated that: "Although the deceased had a major seizure prior to his death but from the details of the history provided it appears it was managed by a staff member. Taking into account the circumstances of the death, together with the findings of this investigation, it is unlikely that the death was linked directly to epilepsy. It is more likely that he died of sudden cardiac death."

An inquest into Clive's death was opened in April 2017, which concluded with a five-day inquest hearing in front of a jury in January 2018. The inquest received and heard evidence from a range of witnesses including Clive's sister, his GP, staff from Cedar Vale, Clive's Consultant Epileptologist and the Pathologist. The inquest was responsible for establishing how Clive died and in what circumstances. We listened to a recording of the inquest and noted that the Pathologist commented on the evidence given by the Consultant Epileptologist and suggested that epilepsy could be added to part 2 of the death certificate. Part 2 of the cause of death is for recording "any other conditions contributing to the death, but not related to the disease that caused it". At the inquest, the Consultant Epileptologist commented that he had not seen the Pathologist's report prior to the hearing, and that in his view the death could be considered a SUDEP.

The final statement from Clive's inquest states that "Clive died of natural causes due to a variety of long-standing medical conditions" which were listed as:

- 1) Ischemic heart disease
- 1b) Coronary atheroma

<sup>9</sup> **Ischemic heart disease** is a term given to heart problems caused by narrowed heart arteries, also known as coronary artery disease and coronary heart disease. ([Definition source: NHS](#))

<sup>10</sup> **Coronary atheroma** is the medical term for the build-up of fatty materials in the arteries. ([Definition source: NHS](#))

<sup>11</sup> **Steatohepatitis** is a type of fatty liver disease, where the build-up of fatty materials in the liver causes inflammation. ([Definition source: NHS](#))

1c) Left ventricular hypertrophy, steatohepatitis and chronic kidney disease.

2) Epilepsy.

Due to the Pathologist's initial finding of ischemic heart disease as the underlying cause of death and his initial exclusion of epilepsy, the significant focus of the inquest was placed on the cardiac event which led to Clive's death. A series of other reviews and investigations also followed Clive's death (see Section 7, part 10: Investigations and reviews following Clive's death) that relied heavily on the pathologist's findings and, in our view, resulted in insufficient attention being placed on other aspects of Clive's care and treatment, in particular his epilepsy care.

This review has carefully considered the relationship between the seizure and the cardiac event that took place on the night that Clive died. We commissioned the advice of an expert Cardiologist who considered the Pathologist's evidence and described the findings as "unremarkable, i.e. the natural wear and tear one would expect to see in a man of his age with hypertension and obesity". He concluded that the cardiac event itself was "not predictable, preventable or avoidable". He also considered the family history and stated that he had "seen no evidence to confirm that Clive had inherited his family's cardiac history".

The expert Cardiologist also stated that he could not rule out the possible compounding influence of other factors that were in operation at the time of his death. These included the potential impact of anti-convulsant and anti-psychotic medication and the reported cases of cardiac rhythm abnormality in patients with Lennox-Gastaut syndrome, as well as transient hypoxia resulting from his frequent seizures and his known obstructive sleep apnoea<sup>12</sup>. In relation to Clive's seizures, he states: "It is well-recognised that epileptic seizures can result in transiently low blood oxygen levels. This would not be expected to have cardiological impact in a normal individual. However, if there is an underlying heart condition that either already restricts the blood supply to the heart muscle (e.g. significant, flow-limiting CAD<sup>13</sup>), or increases heart muscle oxygen demand (e.g. LV hypertrophy<sup>14</sup>), then hypoxia could result in serious heart rhythm disturbance."

We consulted SUDEP Action (a charity working with clinical experts and researchers to better understand and promote understanding of epilepsy-related deaths), who explained the risk of sudden death in epilepsy for someone like Clive who had Lennox-Gastaut syndrome, a complex type of epilepsy with difficult-to-control convulsive (generalised tonic-clonic) seizures<sup>15</sup>. SUDEP is the "sudden, unexpected, witnessed or unwitnessed, non-traumatic and non-drowning deaths in patients with epilepsy, with or without evidence for a seizure, and excluding documented status epilepticus, where necropsy examination does not reveal a toxicological or anatomical cause of death"<sup>16</sup>. We asked SUDEP Action to review the reports written by the Pathologist. They stated that: "the report by the Pathologist refers to his epilepsy and the major seizure just before he died, but concluded that it was unlikely that his death had any connection to his epilepsy. There was no exploration of the role that epilepsy or the seizure played in his death."

<sup>12</sup> **Sleep apnoea** is when your breathing stops and starts while you sleep. It can happen if your airways become too narrow while you sleep, and has been linked to obesity, having a large neck, smoking and drinking alcohol, and having large tonsils. ([Definition source: NHS](#))

<sup>13</sup> **CAD (coronary artery disease)** is when the heart's blood supply is blocked or interrupted by a build-up of fatty substances in the coronary arteries. ([Definition source: NHS](#))

<sup>14</sup> **Left ventricular hypertrophy** is the enlargement and thickening of the walls of the heart's main pumping chamber (left ventricle). ([Definition source: Mayo Clinic](#))

<sup>15</sup> **Tonic-clonic seizures** are the type of epileptic seizure most people recognise. In the past they were called grand-mal seizures. They can have a **generalised** onset, meaning they affect both sides of the brain from the start. ([Definition source: Epilepsy Action](#))

<sup>16</sup> [Nashef, L., So, E., Ryvlin, P. and Tomson, T. \(2012\), 'Unifying the definitions of sudden unexpected death in epilepsy', \*Epilepsia\*, 53\(2\), 227-233](#)

SUDEP Action told us that since 2002, when the National Sentinel Clinical Audit – ‘Epilepsy: death in the shadows’<sup>17</sup> was published, it has been known that SUDEP/epilepsy deaths are routinely underestimated and wrongly ascribed to other causes. They also noted that the casework service at SUDEP Action has seen an increasing trend for epilepsy to be excluded and for investigators to follow a sudden cardiac death pathway instead.

They stated that this has severe consequences – valuable information about how deaths happen and how to prevent them is lost. The audit found that 87% of autopsies carried out into epilepsy deaths were inadequate, leading to inaccurate conclusions. This led to the development of the Royal College of Pathologists (RCP) Guidelines in 2005<sup>18</sup> (updated in 2019)<sup>19</sup> – the blueprint for pathologists to follow when they investigate the death of someone with epilepsy. The Guidelines highlight the problem of the underestimation and mis-categorisation of SUDEP deaths (page 4), recommending that where abnormalities are found, they should be investigated to see whether they may be causative, contributory or neither.

At the time of Clive’s post-mortem in 2017, the RCP Guidelines indicated that the epilepsy history, seizure history and detailed information on the circumstances of the death were required (page 2). This does not appear in Clive’s post-mortem report. The Guidelines also had specific instructions on histopathology<sup>20</sup> – best practice is for a specialist to be involved in the neuropathology interpretation and for whole brain retention and fixation<sup>21</sup> for two to three weeks. Failing that, brain slices can be fixed and then sampled for histopathology. Failing that, “it is essential” that smaller samples be fixed and sampled (page 3). None of this happened at Clive’s post-mortem, although histological examination was carried out on the lungs, heart, kidney and liver.

If the Guidelines had been followed, the relevance of epilepsy and the importance of getting a full history would not have been missed and appropriate investigations might have taken place. In line with the expert Cardiologist’s advice, SUDEP Action also commented that the pathologist’s report noted some abnormalities in the heart – enlarged heart with left ventricular hypertrophy, atheromatous changes to the coronary arteries (up to 50% stenosis) but that there was no evidence of acute ischemia, and that the post-ictal<sup>22</sup> changes to cardiac and respiratory function which can result in SUDEP were not considered. In the context of a witnessed seizure, 50% stenosis (or more) would be appropriately concluded in many cases by some experts<sup>23</sup> to be a SUDEP.

SUDEP is the most common cause of premature death in adults with epilepsy. Sudden death is nearly 24 times more likely in people with epilepsy than in the general population, and the presence of learning disabilities and other co-morbidities (more than one disease or condition) increases that risk. The risk factors for SUDEP are known and many are modifiable.

Clive had many of these risk factors, including the majority of the primary ones:

- Active seizures /refractory (drug-resistant) epilepsy

<sup>17</sup> [Hanna, N.J., Black, M., Sander, J.W.S., Smithson, W.H., Appleton, R., Brown, S. et al. \(2002\), the National Sentinel Clinical Audit of Epilepsy-Related Death: ‘Epilepsy - death in the shadows’, The Stationery Office.](#)

<sup>18</sup> [The Royal College of Pathologists Guidelines on autopsy practice. Scenario 6: Deaths associated with epilepsy \(2005\)](#)

<sup>19</sup> [The Royal College of Pathologists Guidelines on autopsy practice. Deaths in patients with epilepsy including sudden deaths \(2019\)](#)

<sup>20</sup> **Histopathology** is the diagnosis and study of diseases of the tissues, and involves examining tissues and/or cells under a microscope. ([Definition source: The Royal College of Pathologists](#))

<sup>21</sup> As brain tissue deteriorates quickly after death, the brain is sometimes preserved for further examination.

<sup>22</sup> The **post-ictal** phase refers to the period of time immediately following a seizure. ([Definition source: Epilepsy Action](#))

<sup>23</sup> [Nashef, L., So, E., Ryvlin, P. and Tomson, T. \(2012\) ‘Unifying the definitions of sudden unexpected death in epilepsy’, \*Epilepsia\*, 53\(2\): 227–233](#)



- Generalised tonic-clonic seizures: compared to those who do not have GTCS, one or two seizures a year carry a five-times increase in risk; three or more seizures a year can increase risk up to 15 times. The risk increases with the increasing frequency of seizures.
- Nocturnal seizures (during sleep)
- Disrupted sleep often provokes seizures, and we know that Clive's continuous positive airway pressure (CPAP) machine<sup>24</sup> was not available to him in the last months of his life.

Research evidence shows that deaths from SUDEP can be prevented (42% of all deaths and potentially many more). Investigation of the death of someone with epilepsy is vital to inform prevention strategies as well as giving families the answers they need. It should be done consistently and to a high standard (in line with the Guidelines).

In the context of the specialist clinical and academic expertise from SUDEP Action, taken together with the advice of the expert Cardiologist who reviewed the post-mortem report prepared for the inquest into Clive's death and considered that the cardiac findings showed expected wear and tear and were 'unremarkable', we have concluded that the wider context of SUDEP should have been investigated by the pathologist.

Clive's family explained that they had consistently questioned the impact of the severe seizure on Clive's heart on the night that he died, and their legal representatives had requested that the Coroner consider epilepsy evidence in more detail, both at the pre-inquest reviews and during the course of the inquest. It was a matter for the Nottinghamshire Coroner to decide what evidence was placed before her, and she declined these requests. The review fully recognises that any conclusion found at inquest has to be based on evidence heard during the course of the inquest alone. It is up to the Coroner as to the evidence to be heard and considered by a jury, where this must be within the scope of the inquest, which is determined solely by the Coroner.

During the course of this review, we received a letter from the Chief Coroner who provided clarification on the correct mechanism to challenge the findings and conclusion of an inquest. He explained that: "Coroners are judges. Judicial decisions in the Coroner's court, including the decisions of juries, are subject to the review of the higher courts alone. Coroners and juries cannot engage in public debate about their decisions, which means they cannot explain or justify their actions." Following the inquest, Clive's family did seek legal advice in regard to mounting a judicial review on the basis that the Coroner may not have fully met Article 2 obligations. However, they were advised by their legal team that, although there was merit in doing so, the case was borderline, and on that basis would not meet the legal aid test for funding.

The Chief Coroner also stated in his letter: "It may be that the Review has uncovered new information that might justify a second inquest taking place. However, that should be considered through the usual legal channels." This review has set out the expert advice we have received in regard to the cause of Clive's death, including the evidence that the Pathologist did not follow the RCP guidelines when conducting his post-mortem and detailed evidence on the epilepsy care he received. This may constitute 'new information' which Clive's family may present through the appropriate legal channels to request a second inquest from the Attorney General.

Clive's family are one of many families and campaigners who have publicly voiced their concerns about the frequency of 'natural causes' findings in inquests for people with a learning disability. There has also been a series of annual LeDeR reports<sup>25</sup> that have raised concerns about the lower number of inquests conducted into the deaths of people with a learning disability as compared with the general population. In addition, SUDEP Action have presented

<sup>24</sup> A CPAP machine gently pumps air into a mask you wear over your mouth or nose while you sleep, to help reduce the risk of problems linked to sleep apnoea. ([Definition source: NHS](#))

<sup>25</sup> [University of Bristol LeDeR Annual Report \(2020\)](#)

evidence to this review about the significant under-reporting of epilepsy-related deaths and the missed opportunity that this represents to put in measures that could greatly reduce sudden death.

Ten years before Clive's death, the recommendation on SUDEP of a report of the All-Party Parliamentary Group on Epilepsy, 'The human and economic cost of epilepsy in England: wasted money, wasted lives' (2007)<sup>26 27</sup> was for the urgent need to ensure communication of risk and management of risk; a national protocol for investigation of sudden deaths in people with epilepsy and for support of families. It also recommended that the funding and practice of coronial services should recognise the needs of families affected by sudden medical deaths. There is also a clear body of evidence<sup>28</sup> in regard to the circumstances that can result in the early and/or potentially avoidable death of someone with a learning disability. It is important that coroners are equipped with this knowledge, so they are able to deploy their full range of powers to prevent future deaths. This review has welcomed the intervention of the Chief Coroner, and NHSE/I has undertaken to write to him to seek his engagement with these matters of wider concern within the learning disability sector.

Below in part 2: Epilepsy, we review the epilepsy treatment and care Clive received and what was done to mitigate the risks he faced.

## Conclusions and recommendations: Cause of death

**The pathologist did not follow the guidelines on autopsy practice for deaths in patients with epilepsy including sudden death issued by the Royal College of Pathologists<sup>29</sup> which clearly indicated that epilepsy history, seizure history and detailed information on the circumstances of the death were required.**

The Royal College of Pathologists (RCP) should review how effectively pathologists are implementing guidelines on autopsy practice for death in patients with epilepsy including sudden death and consider how it can support and reinforce their professional responsibility to implement these guidelines.

**Clive's family are one of many families and campaigners who have publicly voiced their concerns about the frequency of 'natural causes' findings in inquests for people with a learning disability. The wider concerns expressed by families and professionals in regard to the number, quality and outcome of the inquests of people with a learning disability, together with the evidence on the under-reporting of sudden epilepsy-related deaths should be addressed to the Chief Coroner for consideration.**

There should be a specific communication between the National Director and National Clinical Director for Learning Disability Autism from NHS England and NHS Improvement and the Chief Coroner setting out the concerns from this and other reviews seeking further engagement in the work to prevent future deaths of people with a learning disability.

<sup>26</sup> ['The human and economic cost of epilepsy in England: Wasted money, wasted lives', All Party Parliamentary Group for Epilepsy Report \(2007\)](#)

<sup>27</sup> ['Epileptics' lives lost in care shambles', \*The Guardian\* \(27 June 2007\)](#)

<sup>28</sup> [University of Bristol LeDeR Annual Report \(2020\)](#)

<sup>29</sup> [The Royal College of Pathologists Guidelines on autopsy practice. Deaths in patients with epilepsy including sudden deaths \(2019\)](#)

## 2. Epilepsy

**Clive's epilepsy care overall fell far short of acceptable practice for someone with complex intractable (drug-resistant) epilepsy. At Cedar Vale, his final placement, this placed him at higher risk of sudden death.**

For the reasons stated above, we have carefully reviewed the available evidence on the overall management of Clive's epilepsy, with a particular focus on the way this was managed in his final placement at Cedar Vale.

### Diagnosis and treatment

Clive experienced signs of epilepsy from a young age, but it wasn't formally diagnosed until around the age of 8. At the age of 17, he was diagnosed as having probable Lennox-Gastaut syndrome – a complex, rare, and severe childhood-onset epilepsy. It is characterised by multiple and concurrent seizure types, and typically, it presents in children aged around 3–5 and can persist into adulthood. Records describe Clive experiencing multiple seizure types including complex partial (with automatisms<sup>30</sup> such as fumbling, picking at clothes, repeated leg-crossing), myoclonic (quick, involuntary) jerks, atonic and generalised tonic-clonic seizures. Through his teenage years, seizure activity started to grow and intensify, and at the age of 18 Clive was reported to be experiencing 100 seizures a month.

Clive underwent a right temporal subtotal resection of an astrocytoma<sup>31</sup> on 23 February 1998. It was considered to be slow-growing and did not require treatment beyond surgical resection. For the first time in his life, Clive was seizure-free for the six months that followed. Unfortunately, this was followed by six months of continuous, drug-resistant seizures.

Clive continued to experience seizures throughout his life, with varying degrees of stability. Records indicate that Clive had been prescribed numerous anti-epileptic drugs over the years, but seizures were largely poorly controlled with medication (a common characteristic of Lennox-Gastaut syndrome). Medication and treatments prescribed for Clive's epilepsy were routinely revised and adjusted to stabilise seizure activity as much as possible and balance any side-effects, particularly those affecting Clive's behaviour. The opinion of the expert pharmacist is that it is unclear whether there were major benefits from the various anti-epileptic medication prescribed and how closely this was monitored.

Many evaluations of Clive's epilepsy occurred during his lifetime. An ambulatory 24-hour electroencephalogram (EEG)<sup>32</sup> in 2004 proved inconclusive, so a further detailed evaluation was undertaken at the National Centre for Epilepsy in 2005. A description provided by carers at that review identified five separate seizure types. The outcome from the ambulatory test undertaken at the National Centre for Epilepsy was that he suffered 71 brief sub-clinical seizures<sup>33</sup> in a 21-hour period, mostly occurring in sleep. The findings are consistent with frontal lobe epilepsy<sup>34</sup>.

In 2010, a new Consultant Epileptologist and Neuropsychiatrist took over Clive's care and maintained oversight for the remainder of his life. In 2011, this Consultant sought further

<sup>30</sup> **Automatisms** are non-purposeful, stereotyped, and repetitive behaviours that commonly accompany focal impaired awareness seizures. ([Definition source: MedScape](#))

<sup>31</sup> **Astrocytoma** is the removal of a tumour (see Section 7, part 3: Health inequalities | Brain tumour).

<sup>32</sup> An **ambulatory EEG** is a painless test to record brain activity whilst you go about your routine activities. ([Definition source: Neurology Center](#))

<sup>33</sup> Seizures often cause symptoms like jerking of the body or losing consciousness. When the symptoms of the seizure are not noticeable, it is known as a **sub-clinical seizure**. ([Definition source: Cedars Sinai](#))

<sup>34</sup> **Frontal lobe epilepsy** is the second most common type of epilepsy, where seizures arise in the frontal lobes of the brain. Seizures occurring in these regions of the brain may produce unusual symptoms which can often be misdiagnosed as a psychiatric disorder, non-epileptic seizure or a sleep disorder. ([Definition source: Mayo Clinic](#))

investigations to assess Clive's seizures and to exclude a recurrence of a brain tumour that had previously been surgically removed. This included a 48-hour video telemetry investigation<sup>35</sup>, the results of which he used to develop a short- and medium-term epilepsy management plan. The Consultant concluded that Clive was on too many anti-epileptic drugs at the time. He worked with Clive's family and care providers to better manage Clive's epilepsy, rationalising anti-epileptic drugs to minimise the cognitive and behavioural side effects. He also incorporated non-drug treatments such as changes in diet. Records indicate that it took a few years to rationalise the drugs and it had to be done quite carefully, but Clive was moved onto a better regime. Clive valued the management and continuity of care provided by this Consultant and his team, and the family speak highly of the consistency in support he provided.

The family recall that "a lot of people were involved in Clive's epilepsy from an early age, but there was no coordinated agreed view on how it is best managed. Lots of different medication and interventions were tried." The family were concerned about the level of understanding and management of Clive's epilepsy, and in particular a lack of consistency. Specialist investigations and consistency in specialist clinical oversight played an important role in responding to some of these issues.

## Management and oversight

Research and guidance<sup>36 37</sup> tell us that many people who have epilepsy and a learning disability do not always receive the holistic care they need. They often have many professionals involved in their health and social care and this care can be fragmented. This was evident in Clive's experience.

National Institute for Health and Care Excellence (NICE) Guidelines<sup>38</sup> advise that adults with epilepsy should have a regular structured review with a specialist. They also advise that epilepsy specialist nurses (ESNs) should be an integral part of the network of care for people with epilepsy. The key roles of the ESNs are to support both epilepsy specialists and generalists, to ensure access to community and multi-agency services and to provide information training and support to people with epilepsy, their families and carers. Clive's epilepsy was reviewed by his Consultant Epileptologist and Neuropsychiatrist or a specialist nurse within his team twice a year. While advice was also sought on occasion, expert advice suggests that the complexity and severity of Clive's epilepsy while at Cedar Vale would have benefited from additional direct specialist input and advice to inform his care. Cedar Vale did hold their own monthly multi-disciplinary meetings to review Clive's care, but these were internally focused. Clive would have benefited from the Cedar Vale team working in a multi-disciplinary way with the wider system of professionals engaged in his care.

Records also suggest that Clive's Consultant Epileptologist and Neuropsychiatrist was not always provided with an accurate recording of his seizure activity or experience of day-to-day care on which to advise. Certainly, it was the case that the Consultant was unaware of the fact that Clive had not had use of a working CPAP machine for his sleep apnoea, or the extent to which he had been refusing epilepsy medications, or an up-to-date picture of Clive's seizure patterns, as staff had failed to supply this information at their last appointment in December 2016. These were all matters disclosed to him when he attended the inquest.

<sup>35</sup> A **video telemetry investigation** is a type of EEG which includes video recording. ([Definition source: NHS](#))

<sup>36</sup> ['Step Together: Integrating Care for People with Epilepsy and a Learning Disability', Epilepsy Action \(2020\)](#)

<sup>37</sup> [Kerr, M.P., Watkins, L.V., Angus-Leppan, H., Corp, A., Goodwin, M., Hanson, C., Roy, A. and Shankar, R., The British Branch of the International League Against Epilepsy \(ILAE\) Working Group on services for adults with intellectual disability and epilepsy, 'The provision of care to adults with an intellectual disability in the UK. A Special report from the intellectual disability UK chapter ILAE', \*Seizure\*, Vol. 56 \(March 2018\)](#)

<sup>38</sup> [NICE \(2021\), Epilepsies: diagnosis and management Clinical guideline \[CG137\], Published date: 11 January 2012, Last updated: 12 May 2021](#)



Although it is clear from records that Clive's treatment was overseen by his Consultant Epileptologist and Neuropsychiatrist, 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. For example, in his final placement at Cedar Vale, it does not seem to have been clear if the Consultant, the GP or the Responsible Clinician at Cedar Vale had overarching responsibility for medication.

The 2017 Safeguarding Review following Clive's death found that "Clive's drug card and GP prescriptions did not always reflect consistent prescribing guidelines... Discussion with the GP indicated there had been no changes to his prescription of Senna whilst admitted to Cedar Vale. Cedar Vale management stated: 'It is important to highlight that Clive's prescriber was in fact his Responsible Clinician who recorded the medication, dose, route and time on Clive's medication Kardex. It appears that a GP notification was not sent to his GP who processes the medication prescribed via the Kardex into NHS prescriptions.'"

Other records indicate that the specialist epilepsy clinic was responsible for determining Clive's medication. Expert clinical advice is that the treatment of Clive's epilepsy was linked to his recorded mental disorder, and it was therefore the statutory responsibility of the Responsible Clinician. However, responsible clinicians have a duty to ensure that recommendations from primary and secondary healthcare are implemented.

## **Commissioning and oversight of care provision capable of supporting Clive's epilepsy**

Clive moved through an extraordinary number of care settings in his life, experiencing varying quality of epilepsy care. There are some examples of good care, but for the large part, this review finds that Clive was placed in residential and inpatient settings that were not effectively equipped to meet Clive's epilepsy needs. Consequently, Clive found himself moving frequently, sometimes quite urgently and reactively because of his epilepsy. On one occasion, a care setting was not able to keep Clive safe because of the risks posed by stairs. In other settings, the level of injuries Clive was sustaining due to seizures meant that the service could no longer cope. Many struggled to understand the relationship between Clive's epilepsy and his behaviour.

Clive should not have been placed in services that were unable to demonstrate capability in supporting his complex epilepsy. There appears to have been a lack of specialist epilepsy expertise or epilepsy standards which informed the commissioning of community and inpatient care provision for Clive. Although specifications for Clive's care emphasised the importance of good epilepsy management and care, it is likely that the commissioners responsible lacked the specialist expertise of what good epilepsy care looks like, sometimes acting reactively to find Clive a placement.

Commissioning and regulatory organisations responsible for assessing the quality of care received by Clive also appeared to lack specialist expertise and clear standards in relation to good epilepsy care. Records show that Staffordshire Transforming Care team at South Staffordshire and Shropshire Healthcare NHS Foundation Trust (SSSFT), working on behalf of NHS Stafford and Surrounds Clinical Commissioning Group (CCG), had started a quality review of Clive's care at Cedar Vale in 2016. The quality review template, although detailed, did not require a specific assessment of specialist care such as epilepsy, nor did it appear that commissioners undertaking the assessment had access to specialist epilepsy guidance or expertise. The assessment failed to identify the risks raised by a review of Clive's care records by the Epilepsy Specialist Nurse supporting this review.

## Epilepsy care quality and day-to-day management at Cedar Vale

An independent assessment of epilepsy care at Cedar Vale has been completed for this review by an Advanced Clinical Nurse Specialist in Epilepsy to appraise the quality of epilepsy management and care at Cedar Vale against professional standards of epilepsy care expected in this setting. The findings not only provide an assessment of the standard of epilepsy care at Cedar Vale, but also highlight the potential risks that may have been present for Clive in the other services in which he was placed.

The Epilepsy Specialist Nurse (ESN) explained that the management of Clive's epilepsy care was particularly important because of the risk factors associated with epilepsy-related deaths, including but not restricted to SUDEP. She found that there were major deficits in the epilepsy care provided to Clive while he resided at Cedar Vale, including known risk of epilepsy-related death that Cedar Vale did not effectively respond to, putting Clive, in some incidences, at higher risk of death.

### Epilepsy care planning

NICE Guidelines<sup>39</sup> state that "all children, young people and adults with epilepsy should have a comprehensive care plan that is agreed between the person, family and/or carers where appropriate, and primary care and secondary care providers. This should include lifestyle issues as well as medical issues." The ESN found that the quality of Clive's epilepsy care plan, and importantly its implementation, was inadequate.

The ESN explained that the care team at Cedar Vale needed to fully understand the nature of the Clive's epilepsy, diagnosis, and its treatment as quickly as possible given that they would have no prior knowledge of Clive before admission. A risk assessment, even if one existed prior to admission, would need to be repeated to address the new environmental and care factors. The level of observation required would be a key component of planning this care. The records indicate that St Andrew's Hospital transferred 22 documents about Clive to Cedar Vale and his commissioners on 20 May 2016, which included details of epilepsy appointments. A report detailing Clive's seizures over the last 12 months was also sent by email to Clive's commissioners and the Cedar Vale team on 20 April 2016.

A pre-discharge meeting at St Andrew's Hospital attended by Cedar Vale staff in person, and Clive's commissioners and family by telephone, was held on 26 April 2016. An updated discharge summary was also sent by St Andrew's Hospital to Cedar Vale the day before Clive's admission. Despite these steps, there were important gaps in the receiving care team's information – particularly around the history of Clive's recorded seizures and seizure triggers. The ESN explained that each facility that accepted Clive had the responsibility to ensure that they received the relevant information on his epilepsy care and had a detailed epilepsy care plan in place before Clive arrived in their care.

Multi-disciplinary team (MDT) notes from June 2016 show that a month after Clive's admission, some critical care plans were still in development. Critically, Clive had been admitted to hospital for prolonged seizures in early May, at which point the PRN<sup>40</sup> protocol was not in place, and the seizure response protocol was yet to be reviewed by the MDT and signed off by the Responsible Clinician. No physical intervention protocol was yet in place and Clive's meaningful

<sup>39</sup> [NICE \(2021\), Epilepsies: diagnosis and management Clinical guideline \[CG137\], Published date: 11 January 2012, Last updated: 12 May 2021](#)

<sup>40</sup> **PRN (pro re nata)** means 'when required'. PRN medicines used to manage a person's behaviour should be prescribed for as short a time as possible. Their use should be recorded and reviewed. If you have concern about overuse you should contact the prescriber for advice. ([Definition source: CQC](#))

activity, health promotion and epilepsy care plans were also yet to be reviewed by the MDT. Risk and capacity assessments were also yet to be completed.

## Epilepsy management and oversight

Clive's epilepsy care plan stated that: "all seizure activity is to be documented on individual seizure recording charts. This is to include presentation prior, during and post-seizure activity and recordings are to be kept behind the epilepsy care plan." It is the view of the expert ESN that seizure descriptions were not clear and a review of care records indicates that the quality of seizure recording as mandated by the plan was poor.

Cedar Vale did not have specialist expertise on site, and did not often access the specialist epilepsy expertise required to meet Clive's needs. Records indicate that specialist advice on Clive's epilepsy care plan required of Clive's Consultant Epileptologist and Neuropsychiatrist was not always sought, as recommended, and that communication and engagement of the team outside of Clive's review meetings was limited. For example, shortly after his admission, Clive was admitted into hospital for prolonged seizures and discharged with the recommendation that a follow-up appointment with the neurologist should be organised in order to optimise anti-epileptic medication in view of increased seizure activity. This does not appear to have been followed up. On another occasion shortly after Clive's arrival, there is an action from the MDT that the seizure protocol needed input from Clive's neurology team as it "did not outline what specific course of action to take when a mixture of seizures is experienced". This was an outstanding action for several months.

Clive's epilepsy care plan states that all seizure activity is to be reported to the Responsible Clinician and reviewed via the MDT, so that concerns can be referred to Clive's Consultant Epileptologist and Neuropsychiatrist and Epilepsy Specialist Nurse. The record of seizures provided to monthly MDT meetings lacked detail – as did the level of discussion in relation to Clive's epilepsy indicated by MDT notes. There is no evidence to suggest documented issues such as poor sleep, thought to potentially impact on prolonged seizures, were referred to Clive's Consultant. The expert ESN also advises that there was a significant absence of close collaboration on the management of Clive's epilepsy alongside the management of his mental health.

## Risk of epilepsy-related death including (but not restricted to) Sudden Unexpected Death in Epilepsy (SUDEP)

The ESN explained that Clive should have been recognised as someone who was at a high risk of death from epilepsy because of his complex epilepsy syndrome, even if compliant with treatment. Although this is a risk in all epilepsy types, it is higher in Lennox-Gastaut syndrome.

SUDEP is the "sudden, unexpected, witnessed or unwitnessed, non-traumatic and non-drowning deaths in patients with epilepsy, with or without evidence for a seizure, and excluding documented status epilepticus, where necropsy examination does not reveal a toxicological or anatomical cause of death."<sup>41</sup> The incidence of sudden death is up to 24 times higher in people with epilepsy compared to the general population, and SUDEP is the most important direct epilepsy-related cause of death. It is the leading cause of death in people with uncontrolled seizures. It is suggested that SUDEP rates can be as high as 42% in people such as Clive who have over 15 years' history of drug-resistant seizures.

In England, it is reported that 'convulsions and epilepsy' accounted for more than 40% of all emergency admissions for ambulatory care sensitive conditions (ACSCs) for people with a

<sup>41</sup> [Nashef, L., So, E., Ryvlin, P and Tomson, T. \(2012\), 'Unifying the definitions of sudden unexpected death in epilepsy', \*Epilepsia\*, 53\(2\), 227–233](#)

learning disability<sup>42</sup>. This is characteristic of Clive's experience – there are many instances in Clive's records which document admission to A&E as a result of seizures. Following his admission to Cedar Vale, Clive was admitted to A&E or paramedics were called on five occasions in eight months. NHS Right Care Epilepsy Toolkit<sup>43</sup> suggests that high A&E attendance should be flagged as a potential risk factor to identify people at risk of premature death.

A specific epilepsy care plan and rescue protocol was in place for Clive at Cedar Vale to support the overall management of Clive's epilepsy. This did identify that Clive was at high risk of SUDEP, placed Clive on one-to-one observation, and staff were asked to monitor and record his seizures. However, the specialist expertise to implement the epilepsy care plan effectively or to respond to the higher risk of sudden death that Clive faced due to his diagnosis of Lennox-Gastaut syndrome, appears to be lacking.

The ESN's view is that in addition to a detailed care plan, there should also have been a comprehensive risk assessment that ensured that all risks were detailed with mitigating actions. In review of Clive's care records, she found:

- Insufficient evidence of an epilepsy risk assessment. A generic high-level risk screening and assessment tool identified Clive's epilepsy as high-risk and Clive's epilepsy care plan makes reference to SUDEP, but both lack detail in relation to the nature and management of risk.
- Clive was on level 3 (within eyesight) one-to-one observation during waking hours and while asleep. Clive's allocated staff were to remain outside his bedroom while Clive was asleep, and a seizure bed alarm was in place to alert staff if a seizure occurred. However, records indicate that seizure monitoring and recording was not consistent and of a poor quality. Seizure descriptions were not always clear, and there are concerns about the knowledge of staff in relation of seizure triggers and signs.
- There were no specific details in the care plan requiring staff to observe for signs of breathing – not just signs of Clive having a seizure.
- Some of the care staff at Clive's inquest reported to be agency staff who had limited experience of working with Clive.
- There was no evidence of a bathing and showering risk assessment.
- Prevention of head injury (particularly if a diagnosis of tonic or atonic seizures has been made) is important, as accidents are a significant cause of avoidable deaths. A protective helmet was prescribed to prevent head injury, and records show that Clive had previously understood its importance and was compliant with wearing it at all times. At Cedar Vale, records report that Clive did not always wear the helmet and there was no specific epilepsy plan in place to support Clive to wear it – taking into account his capacity to make an informed decision about not wearing it and the risks associated. When the protective helmet was broken, this was not urgently dealt with.

## Mental capacity

A major concern of the ESN was that she had seen no evidence of a proper assessment of Clive's mental capacity in relation to his epilepsy treatment for the majority of his time at Cedar Vale. She noted that there were conflicting views on his capacity. A capacity assessment in May 2016 indicated that he did have capacity in relation to his medication. However, from September 2016, it appears that Clive was deemed not to have capacity in regard to his medication. Staff

<sup>42</sup> [Glover, G. and Evison, F. \(2013\), 'Improving Health and Lives: Learning Disabilities Observatory – Hospital admissions that should not happen'](#)

<sup>43</sup> [NHS RightCare: Epilepsy Toolkit \(2020\)](#)



understanding and application of the Mental Capacity Act is also an issue raised in Care Quality Commission (CQC) inspections for Cedar Vale following Clive's death.

The ESN explained that the assessment relating to Clive's mental capacity to the treatment for his epilepsy and other aspects of physical healthcare would not be covered by the Mental Health Act assessment for capacity in relation to his psychiatric treatment: "The lack of a definitive MDT decision on his mental capacity in relation to his epilepsy treatment, confusion and differing opinions in his care team in relation to capacity had serious and profound implications to the treatment of his epilepsy. In particular, the most risky single effect on his seizure control was his poor medication compliance."

## Epilepsy medication

The expert Pharmacist has provided a detailed examination of the epilepsy medications Clive was prescribed. He notes that Clive was prescribed a wide range of anti-epileptics during his life, which was a common experience of people who suffer refractory epilepsy. The failure to respond to the exposure of such a wide range of anti-epileptics is also a common feature of Lennox-Gastaut epilepsy. Despite the availability of many new anti-epileptic medications with differing mechanisms of action, he noted that overall outcomes did not improve for Clive. Overall, his view is that the prescribing practice was generally in line with what might be expected for someone with Clive's profile of drug-resistant epilepsy.

The main question in regard to Clive's epilepsy medication is the impact of missed medication and how this was managed in the last weeks of his life. Sometimes Clive refused medication, and sometimes it was missed because he was sleeping. The expert Epilepsy Nurse commented that "the staff members administering the medication appeared to believe that he had capacity to make the decision to refuse his medication and that it was his choice." She observed that the care plan for refusal of his medication stated he was to be offered the medication on four occasions with the implication that he had the mental capacity to make that decision. If it was assumed that he had capacity this would be a reasonable strategy, assuming staff also informed him of the risks of not taking his medication. Given the severity of his epilepsy, non-compliance with medication would be associated with an increased risk of death. Such a decision in his circumstances would be considered an unwise decision, and Clive should have had a detailed capacity assessment leading to a detailed advanced care plan and risk minimisation plan developed with him. We have not seen any evidence that, in line with the MCA, any attempt was made to work with Clive to support his understanding of the importance of taking his medication. This should have happened, regardless of the outcome of any capacity assessment.

If Clive was unable to understand the consequences of not taking his medication as prescribed, then he could not have made a capacitated decision around the medication for epilepsy. The ESN explained that if Clive had lacked capacity (as indicated at September 2016: see above), the care team should have made a best-interest decision relating to epilepsy medication. This would have needed to include a clear account of the implications of not taking anti-epileptic medication as prescribed, and considering the necessity and proportionality of any alternative medication administration strategy, which could include various stages of increasing restriction up to and including a covert administration plan if deemed necessary and proportionate.

The absence of evidence to a capacity-based approach being taken in regard to Clive's epilepsy medication, suggests that the nursing staff on the unit were not fully aware of the risks of non-compliance with medication in relation to his epilepsy. This is further reinforced by the fact that Clive's Responsible Clinician at Cedar Vale confirmed at the inquest that the nursing team had not escalated that Clive was refusing/not being given medication when he was asleep. This was also the finding of the safeguarding review following Clive's death, which

reported that the Cedar Vale team had failed to sufficiently recognise the negative consequences of missing prescribed anti-epileptic medication.

In the view of the expert Epilepsy Nurse, the significance for his health in non-compliance with psychiatric medication and anti-epileptic medication should have been treated differently: “Whereas non-compliance with psychiatric medication may have had a negative effect on his mental health and behaviour, non-compliance with anti-epileptic therapy was life threatening and this needed to be reflected in his care.” Her report states that for patients with Lennox-Gastaut syndrome, the refractory and intractable (drug-resistant) nature of the condition and the frequency and severity of seizures means that non-compliance with medication has an even greater impact. She concludes that: “If this pattern of non-compliance with his epilepsy treatment had continued, then it would be predictable that his risk of an epilepsy related death would be high.”

The expert Pharmacist was unable to be conclusive on this point, stating that: “despite the availability of thousands of pages of notes, letters and other documents relating to Clive’s life, there was a lack of objective data about whether the medications impacted on his epilepsy. This severely hampered my ability to make confident statements about the potential impact of his medications on his death.”

## **Sleep apnoea, CPAP (continuous positive airway pressure) and epilepsy**

Shortly after moving to St Andrew’s Hospital in 2012, Clive underwent a 24-hour sleep assessment, which showed that he was waking due to shortness of breath around 60 times an hour. Clive was diagnosed with obstructive sleep apnoea and prescribed a CPAP machine to be worn at night (see Section 7, part 3: Health inequalities | Sleep apnoea). Records indicate that the seriousness of the risks associated with sleep apnoea to Clive’s epilepsy were not always fully understood by the team caring for Clive at Cedar Vale. Clive’s sister felt that staff appeared to show no interest in, or understanding of, its use. Staff, particularly agency care staff observing Clive at night, reported that they did not have training on sleep apnoea or the use of CPAP machines.

Clive did not have access to a CPAP machine in the last seven weeks of his life. It was broken beyond repair at the beginning of December 2016 and was awaiting a replacement, for which there had been delays. At the inquest, Clive’s Consultant Epileptologist and Neuropsychiatrist suggested that the CPAP was significant and, had he known that it had been broken, he would have expected it to be repaired within a day or so. When asked at the inquest what he considered to be the biggest risk of not using a CPAP machine, the Consultant reported: “In the short term a likelihood of more seizures, more sleepy in the day time, irritable, less concentration. Longer-term hypertension and increased risk of heart attack.”

The expert Pharmacist concluded that it is not possible to say if a working CPAP machine would have directly reduced the likelihood of Clive’s death. However, it is evident that the Cedar Vale team did not provide sufficient support to increase compliance, or put in place mitigating actions for non-compliance, and did not appear to understand the contribution the intervention could make in reducing seizure activity or its role in helping to reduce the risk of SUDEP. The expert epilepsy nurse has stated that the lack of the CPAP machine may have impacted on his epilepsy. In our view the failure of the team to support Clive to use it further increased his risk of premature death.

## **Cedar Vale staff training on epilepsy**

It was evident that most of the Cedar Vale staff, especially those who were agency staff, had received generic mandatory epilepsy training and that this had been delivered mainly through online learning modules. In practical terms, given the reported staff turnover and the frequent

use of agency staff, especially during the night, it is likely to be the case that Clive was generally not being supported by staff with the necessary expertise for the degree of complex and drug-resistant epilepsy he experienced. Critically, staff did not appear able to make sufficiently accurate records of the type and duration of his seizures of a quality that would have assisted any review of his epilepsy or to escalate appropriately the issues of non-compliance.

## Epilepsy and challenging behaviour

Clive experienced behaviours that were deemed to be challenging. Records indicate that care providers often struggled to understand the underlying cause of this behaviour and to separate out the specific impact of his epilepsy from wider factors. Deb (2006)<sup>44</sup> argued that it is imperative to find out the cause and consequences of behaviour problems before deciding on an appropriate management strategy, and understanding the relationship between epilepsy and behaviour is paramount when trying to assess the reason for, or purpose of, the behaviour.

The overwhelming view across the specialist hospitals in which Clive was detained and the community care settings in which he lived was that Clive's behaviours arose from his epilepsy and acquired brain injury. Consequently, a more medical and containment approach was taken – with a significant focus on epilepsy management and reactive approaches to behavioural presentation (see Section 7, part 5: Specialist hospitals). However, it was not clear how this assessment was monitored and verified over time.

The discharge summary from St Andrew's Hospital states: "It is safer to assume that any unusual behaviour displayed is related to complex partial seizure<sup>45</sup>... It is difficult to define the [Clive's] behaviour as an aggressive behaviour as it tends to occur mainly within the context of seizures. The psychological definition of aggression requires the presence of conscious intention. Complex partial seizure is a state of impaired consciousness hence the definition of aggression cannot be applied accurately."

Drawing on a two-day telemetry assessment in 2011, Clive's Consultant Epileptologist and Neuropsychiatrist reported some observed patterns in behaviour linked to a six-week cycle that included two weeks of seizures, two weeks of relative stability and then two weeks of more challenging behaviours. It is also recognised that psychiatric and behavioural side effects are common, undesirable effects associated with anti-epileptic medication use, as confirmed by the expert Pharmacist supporting this review. Levetiracetam, which Clive had been taking, is reported to have the greatest psychiatric and behavioural side effects. Records demonstrate that treatments were adjusted over the years to minimise these side effects.

However, Clive's Consultant also reported to the Coroner's inquest that many incidents of behaviour deemed to be challenging were unrelated to seizures, seemed to occur when Clive was more well, and were likely to be impacted on by wider factors affecting his mental health. The expert Pharmacist was also of the opinion that "fluctuations in his [Clive's] seizure pattern and behaviour seem more associated with other factors in his life rather than medications."

We asked the expert ESN to consider this aspect of his assessment and treatment, and she explained that: "In Lennox-Gastaut, there is an association between cognitive dysfunction, anxiety, irritability, depression, aggression and behaviour problems, which can significantly impact on a person's mental health and wellbeing." However, she further explained that there may have been a number of influences on Clive's behaviour and that "a comprehensive function analysis of the association between behaviour and epilepsy i.e. Pre-ictal and post-ictal

<sup>44</sup> Deb, S. (2006), 'Medication for behaviour problems associated with learning disabilities', *Psychiatry*, 5:10, 368–371

<sup>45</sup> A **complex partial seizure** is a type of seizure that arises in one lobe of the brain, rather than the whole brain. The seizure affects people's awareness and may cause them to lose consciousness. ([Definition source: Medical News Today](#))

psychosis should have been assessed”, commenting that it was “unclear to what degree this [epilepsy] affected his presentation”, but that “it was unlikely to be a primary or key factor”.

The lack of concrete understanding about the association between Clive’s epilepsy and behaviours deemed to be challenging had a profound impact on his life. Detention could have been avoided or ended sooner had there been better comprehensive understanding and support of Clive’s behaviour. Instead, the view that Clive’s behaviour was largely to do with his epilepsy and was unchangeable meant that there was a view that hospital was the only option for him. For the large part of Clive’s stay in hospital, providers did not pursue fully the possibilities for reducing and mitigating risks that would have enabled a move back into the community. The consequence of the limited formulation (linked to epilepsy) and understanding of behaviour meant that Clive did not, for much of his life, receive the right care and support he needed for his epilepsy or behaviour.

In the absence of sufficient functional analysis of Clive’s presenting behaviours throughout much of his life, we conclude that the link between Clive’s epilepsy and challenging behaviour was overstated and disproportionately impacted on the generally held view that Clive required a hospital setting, depriving him of the opportunity to better manage his behaviours and prolonging his detention. The review concludes that better guidance is needed for care professionals around challenging behaviour linked to epilepsy and its management.

## Conclusions and recommendations: Epilepsy

**Commissioning of care for people with a learning disability and epilepsy: Clive should not have been placed in services that did not and could not meet his needs with regard to epilepsy care.**

In commissioning care provision (specialist hospital or community) for people with a learning disability and epilepsy, commissioners at a local level (health and social care) should actively assure themselves that care providers are delivering a standard of epilepsy care that is compliant with NICE standards.

Commissioning organisations at a local level (health and social care) should ensure that commissioners of care provision for people with a learning disability are equipped with or able to access specialist epilepsy expertise to commission safe and effective care for people with a learning disability and epilepsy.

Regional NHSE/I Learning Disability and Autism Programmes should undertake a capacity and training needs audit to review the capacity and skills of staff to commission safe care for people with a learning disability who have complex needs including epilepsy.

**Epilepsy care coordination and management: Management and oversight of Clive’s epilepsy care was often fragmented, and it was not always clear who was responsible overall.**

Commissioners of care for people with a learning disability at a local level (health and social care) must take action to assure themselves that there is effective coordination between the professionals in primary, secondary and community care who are supporting an individual with complex needs and that there is a clearly identified lead. This is necessary in order to provide holistic, person-centred care.

Commissioners responsible for epilepsy care at a local level should undertake an audit of the effectiveness of local epilepsy services and support for people with a learning disability drawing on the NHS Right Care Epilepsy Toolkit<sup>46</sup> and NICE standards to ensure they are

<sup>46</sup> [NHS RightCare: Epilepsy Toolkit \(2020\)](#)



meeting the needs of people with a learning disability and epilepsy, and that they are compliant with NICE standards of care.

**Care quality and safety: The standard of epilepsy care Clive received in specialist hospital and community residential care settings was often poor and his high risk of epilepsy-related death and sudden death was not always effectively recognised and mitigated.**

Care providers (specialist hospital and community) must ensure that the care they provide for people with a learning disability and epilepsy is compliant with NICE epilepsy care standards and that all staff are trained in full to meet these standards.

Commissioners of care for people with a learning disability and epilepsy must ensure that care and service providers take a risk management approach to epilepsy-related death, as recommended in the NHS Right Care Epilepsy Toolkit. This should specifically include application of a standard risk template for people living with epilepsy that crosses organisational boundaries, such as the SUDEP and Seizure Safety Checklist<sup>47</sup> tool.

**Epilepsy and challenging behaviour: The link between Clive's epilepsy and challenging behaviour was overstated and disproportionately influenced the generally held view that Clive required a hospital setting, depriving him of the opportunity to better manage his behaviours, and prolonging his detention.**

With a view to providing better guidance for clinicians, carers and care professionals in relation to epilepsy and challenging behaviour linked to epilepsy and its management, the National Institute for Health and Care Excellence (NICE) should consider reviewing current guidelines in relation to:

- epilepsy and special consideration for people with a learning disability
- challenging behaviour and learning disabilities.

<sup>47</sup> [SUDEP Action: SUDEP and Seizure Safety Checklist](#)

### 3. Health inequalities

**Clive experienced health inequalities from a young age that had a negative impact on his quality of life, some of which caused him pain and suffering for prolonged periods of time and placed him at risk.**

Clive's family describe some very good experiences of healthcare for Clive. These include the weeks he spent at Northampton General Hospital following an ankle fracture in April 2016, the care he received when undergoing brain surgery in earlier years, and the care he received from his Consultant Epileptologist for many years.

However, he also faced health inequalities from a young age. Most commonly, Clive's epilepsy came to define him, and there was a tendency for health professionals to attribute wider health complaints to epilepsy (known as diagnostic overshadowing<sup>48</sup>). Health and care professionals did not always effectively assess the pain he was in, did not always listen to his family who knew him best, and failed to lower the threshold of suspicion when diagnosing conditions, and failed to make the reasonable adjustments Clive required to help him access healthcare.

Clive was generally supported to access routine health appointments, including those with opticians, dentists, his GP and annual health checks. Records indicate that he was also routinely referred for specialist assessment of specific physical health issues when these arose. However, not all of these conditions appear to have been treated in a timely, consistent or appropriate way. As Clive moved through different placements, there were occasions when some providers did not pass on or follow previous medical, prescription or treatment advice.

When Clive moved to Cedar Vale, he was registered with a local GP on 3 May 2016. The records show that this practice, despite not having been sent Clive's full medical history, commenced a series of referrals to address a range of conditions. These included a referral for follow-up at a fracture clinic, a referral to have ear wax removed, a referral for a replacement epilepsy helmet and to a respiratory clinic for his 'CPAP machine to be checked'. The records also show that they conducted a routine electrocardiogram (ECG) as part of his medication review (see Section 7, part 3: Health inequalities | Cardiology), together with completing Clive's annual health check.

However, it is also evident that Clive did not attend all of the hospital appointments. The monthly multi-disciplinary team (MDT) meetings at Cedar Vale in July, August, and September 2016 record recurring actions to book optical, hearing and dental appointments. MDT records also note that three appointments had been declined by Clive since admission and that he had also refused to see a dentist.

Clive's family explained that, in their view, Cedar Vale failed to recognise the support Clive needed in attending hospital appointments and failed to make the reasonable adjustments that would have supported him to access appointments. The review finds that the barriers that Clive experienced to accessing healthcare, and his refusal to attend, were not always fully understood or addressed. Cedar Vale failed to understand Clive's needs and anxieties in relation to getting to appointments and failed to make reasonable adjustments to enable him to attend.

Clive's family explained that in previous settings, staff had recognised the importance of him feeling comfortable with the staff who went with him to appointments. Clive's family also frequently attended Clive's appointments with him and knew that he was happy to attend when he felt he had trusted support. However, at Cedar Vale, the letters for appointments did not

<sup>48</sup> **Diagnostic overshadowing** occurs when someone, usually a healthcare professional, assumes that a person's presentation is due to their disability or coexisting mental health condition rather than fully exploring the cause of person's symptoms or presentation.

always come to the family as requested, which meant that they had been unable to help support Clive and ensure he got to his medical appointments.

## Clive's health

Clive had a number of different health conditions where the evidence shows his treatment fell short of acceptable practice.

### Brain tumour

There were missed opportunities to investigate and treat Clive's brain tumour sooner, which could have prevented the unacceptable and prolonged suffering of the symptoms he endured.

Clive's family recall that by the time he was about 8 years old, he was presenting regularly to A&E and as a result he was referred for further investigations by a consultant neurologist/psychiatrist at Queen Elizabeth Hospital, Birmingham. Clive was referred for a magnetic resonance imaging (MRI) scan as part of a range of assessments that would later confirm that he had epilepsy. A small pinhead-pin-head-sized lesion was detected on the MRI scan, but they were told that there was nothing to worry about and "they would keep an eye on it". There are no records of this scan. The records show that there was an MRI scan in 1986, but this did not report on an abnormality of that type.

In the mid-1990s, Clive's seizure activity and health deteriorated rapidly. The family describe him returning to the days of his early years, bedridden in a dark room, suffering from severe pain in his head, vomiting and not being able to stand up. Initially the terrible headaches were thought to be severe migraines; which the family say were ongoing for a number of years. The family raised their concerns about Clive's headaches many times, fearing that too much attention was being placed on Clive's increased seizure activity and behaviour, and not enough on the severe headaches and their associated symptoms.

Eventually Clive was referred for a CT scan on 22 September 1997 by his consultant neurologist. The scan showed what doctors suspected to be cystic astrocytoma – a brain tumour – and Clive was referred for an urgent MRI scan on 31 October 1997. The MRI confirmed the tumour, and Clive was referred to a consultant neurosurgeon at the Royal Infirmary, Stoke-on-Trent, for treatment. Records state that, in the absence of any previous scans, it is not clear how long the tumour had been there or whether it was having an impact on his increased seizures. Clive was placed on a waiting list to be brought in as soon as possible for surgery.

It came as a complete shock to Clive's family when, at the end of February 1998, they received a call "out of the blue" to discuss the treatment options for Clive and were told that he must urgently be brought into hospital to undergo surgery. Only then did they become aware that investigations had taken place and that Clive had been diagnosed with a brain tumour requiring urgent surgery. They also report that they were deeply shocked to discover that there had been a delay of several months for his test results to be transferred to the consultant, due to the clinician responsible going on annual leave.

Clive underwent a right temporal subtotal resection of an astrocytoma (removal of tumour) on 23 February 1998. It was considered to be slow-growing and did not require treatment beyond surgical resection. The surgery was successful, and the family recall when Clive awoke, his first realisation was that his headaches had gone. The surgery affected Clive's short-term memory, but his long-term memory remained unaffected. For the first time in his life, Clive was seizure-free for the six months that followed. Unfortunately, this was followed by six months of continuous drug-resistant seizures. The family speak highly of the surgeon who performed the surgery. They also report that he heard their concerns about the quality of Clive's care at Richmond Mews, and was instrumental in ensuring that Clive was discharged back home.

Clive's family are understandably concerned that opportunities for the tumour to be diagnosed (for example through more frequent MRI scans) were missed. Due to the absence of medical records at the time, it is difficult to assess what investigations took place. However, the family report that the headaches were assumed to be severe migraines. They believe that, had the necessary investigations taken place earlier, Clive could have been spared the suffering of symptoms he endured for years before the MRI scan. Indeed, the family feel that it could have been identified by the pinhead shadow detected by an MRI in his early years.

The family account does suggest that doctors may have been so focused on assessing Clive's epilepsy that something may have been missed. It is likely that Clive experienced prolonged periods of suffering from the pain associated with the brain tumour, while clinicians believed that his symptoms were associated with his epilepsy or were migraines. This is an example of 'diagnostic overshadowing'. There was also a delay in arranging his surgery, which would have caused him a further period of pain and distress. There is no evidence to suggest that pain tools were used to assess the amount of pain Clive was in, but based on the accounts given by his family, it is clear that he experienced a great deal of pain and suffering during the years leading up to the removal of the tumour and that this had a huge impact on his quality of life.

## Sleep apnoea

Shortly after moving to St Andrew's Hospital in 2012, Clive underwent a 24-hour sleep assessment, which showed that he was waking due to shortness of breath around 60 times an hour. Clive was diagnosed with obstructive sleep apnoea and prescribed a CPAP (continuous positive airway pressure) machine to be worn at night.

Early records indicate that staff noticed a visual improvement in his sleep after the introduction of the CPAP machine. Progress was monitored annually by the Respiratory Clinic at Nottingham University Hospital, which was noted as positive at the 2013, 2014 and 2016 review, although the clinic was unable to confirm compliance from data generated by the machine as it had not been taken to the appointment.

Care records indicate that Clive understood the importance of the CPAP machine, and was compliant with it overall while at St Andrew's Hospital, but less so at Cedar Vale. On occasions he would damage it in times of distress. Clive's family report that he was generally compliant with wearing the mask, even though he found it uncomfortable, up until shortly before he left St Andrew's Hospital. His sister commented that there were times when Clive chose not to wear it. Although there were a small number of occasions when he had broken it, she said that generally he only refused when it was not working properly or needed cleaning.

In transferring to Cedar Vale, the Transforming Care team at South Staffordshire and Shropshire Healthcare NHS Foundation Trust (SSSFT) stressed the importance of the CPAP machine and arranged for some staff to receive training in its use at the outset. The importance of this CPAP machine is clearly recorded in Clive's health promotion care plan at Cedar Vale, which notes that he must always have his mask on at night with one-to-one observation. It states that Clive should be: "encouraged to wear the machine throughout the duration of the night, but closer observations can be placed on Clive to observe him for breathing difficulties if persuasion is not effective. However, these instructions must be documented, and the MDT must be informed of this if it does occur. It is important that Clive's staff team remain vigilant to the symptoms of sleep apnoea to continually assess any deterioration in the condition, or any signs that the present treatment is no longer working."

However, records indicate that the seriousness of the risks associated with sleep apnoea, particularly for Clive's epilepsy, were not always recognised. Clive's sister said that staff appeared to show no interest in, or understanding of, its use. Staff, particularly agency care staff observing Clive at night, reportedly had no training on sleep apnoea or the use of CPAP



machines. Care staff supporting Clive at night did not necessarily know him very well and some had worked with him a handful of times, many of those while he was sleeping.

On 25 November 2016, concerns were also raised by the Responsible Clinician when he visited Clive and found him not to be wearing his CPAP machine and having apnoeic episodes in his sleep. The Responsible Clinician advised that Clive required bed head elevation if the CPAP was not working or was being refused, and requested that the old (profiling bed) be moved to his room urgently. This had not been implemented by the time of the next multi-disciplinary team meeting on 13 December.

On 11 December 2016, Clive's CPAP machine was damaged irreparably and he was without a working CPAP machine in the last seven weeks leading up to his death. There were delays in following up the replacement of the CPAP machine, and a lack of clarity among staff about who was responsible for its repair.

We do know from care records that Clive's sleep apnoea was getting worse in the months leading up to his death. However, a lack of objective data makes it difficult to conclusively confirm the potential impact of the lack of compliance with the CPAP machine, and in the final months, its lack of availability to Clive all together.

The expert Pharmacist is of the view that, with good compliance, CPAP had the potential to significantly improve Clive's daytime drowsiness and general health, with the additional benefits of reduced seizure frequency and lower risk of SUDEP. However, poor monitoring means there is no documented evidence that any of these potential gains occurred with Clive. The expert Pharmacist suggests that a proper assessment of the value of the CPAP should have taken place in 2012, and, if there were no benefits, it should have been withdrawn if there were no benefits. In view of the poor compliance and lack of *evidenced* benefits, he is of the view that it is unlikely that the availability of a working CPAP machine would have reduced the likelihood of the unexpected death.

At the inquest, Clive's Consultant Epileptologist and Neuropsychiatrist suggested that the CPAP was significant, and had he known that it had been broken, he would have expected it to be fixed within a day or so. When asked what he considered to be the biggest risk of not using a CPAP machine at the inquest, the Consultant reported: "In the short term, a likelihood of more seizures, more sleepy in the day time, irritable, less concentration. Longer-term hypertension and increased risk of heart attack."

While we agree with the expert Pharmacist that we are unable to say if a working CPAP machine would have directly reduced the likelihood of Clive's unexpected death, it is evident that the Cedar Vale team did not provide sufficient support to increase compliance, and did not appear to understand the contribution the intervention could make in reducing seizure activity or its role in helping to reduce the risk of SUDEP. The expert epilepsy nurse has stated that the lack of the CPAP machine may have impacted on Clive's epilepsy.

Guidance<sup>49</sup> makes it clear that the responsibility for using and maintaining prescribed medical equipment, as in the case of the CPAP machine, is the provider's responsibility and should have been overseen by both the commissioner of the service (under the Health and Social Care Act 2008) and the Care Quality Commission under Regulation 15<sup>50</sup>. Regulation 15 states that regulators must make sure that "the equipment that is used to deliver care and treatment is clean, suitable for the intended purpose, maintained, stored securely and used properly", that "Providers retain legal responsibility under these regulations," and that "They must therefore make sure that they meet the regulation, as responsibility for any shortfall rests with the provider."

<sup>49</sup> ['Equipment Standards, Guidance and Legislation', EBME \(28 September 2019\)](#)

<sup>50</sup> [Care Quality Commission Regulation 15: Premises and equipment. Last updated: 19 February 2019](#)

While the CQC cannot prosecute for a breach of this Regulation, they can take regulatory action, such as refusing registration if providers cannot satisfy them that they can or will comply with this Regulation. The only reference to the use of medical equipment in the Cedar Vale inspection reports between 2016 and 2019 is in their report dated 13 January 2017, the month in which Clive died, which. This report notes that: “Some equipment had not been checked and calibrated to ensure it was safe to use. This was rectified on the day of the inspection.” No further action appears to have been demanded by the regulator.

If the team at Cedar Vale had concerns about the effectiveness of the device and concerns about Clive’s compliance in using it, in particular when it was broken, they should have made an immediate referral to the Respiratory Consultant who prescribed it, and taken mitigating action in the meantime. While the records show an appointment with the Respiratory team was scheduled in the February following Clive’s death, this left Clive without use of the CPAP machine for at least seven weeks prior to his death. The adult safeguarding review following Clive’s death specifically recommended that Cedar Vale “review the provision, maintenance and management of equipment used within Cedar Vale for its residents – this should include review of cleaning, maintenance and repair logs”.

In our view, the failure of the team to support Clive to use the CPAP machine and ensure that it was properly maintained and repaired further increased his risk of premature death.

## Cardiology

Clive’s family told us that they strongly believe Clive had an inherited family heart condition which was not investigated – despite the family having alerted doctors to this concern many times. On reading the Pathologist’s report (see Section 1: Foreword), they understandably concluded that the failure to investigate their concerns was directly related to Clive’s cause of death. However, the expert Cardiologist stated that there was no evidence to suggest that Clive had this condition, and that the cardiac event on the night he died was “neither predictable, preventable or avoidable”.

Clive reported having chest pains to staff on a regular basis. His care records document that this had been ongoing since 2012 and continued up until he died. Routine investigations into the chest pains were explored while he was at St Andrew’s Hospital. This included a review by the hospital GP and referrals for electrocardiogram (ECG) which revealed no abnormalities. However, Clive continued to experience discomfort and was prescribed the drug Omeprazole in January 2015 for upper gastric discomfort. This appears to indicate that they had concluded that his chest pain was not cardiac-related.

On 13 December 2016 – shortly before his death – Clive attended his GP for a routine annual ECG recording. This was a requirement for the prescription of the anti-psychotic medications he was taking. He was noted to be clammy and there were concerns about his ECG tracing. When asked, Clive also reported chest pain, prompting him to be sent to A&E that day. There, it was noted that intermittent chest pain had been a feature for five years and when assessed in A&E his pain score was 3/10. The results of further tests did not indicate that there were issues of concern, but staff were asked to refer Clive back via his GP for further investigations if he continued to complain of chest pain. This did not happen, as the team at Cedar Vale remained convinced that the pain Clive reported was not cardiac-related (inquest evidence). At the inquest, they also said that they believed that he was sometimes ‘faking’ the pain.

Beyond the routine assessments, the expert Cardiologist noted that Clive was not referred for any further detailed assessments and recommended that: “Given a significant family history, Clive – like any other family member – should have received a detailed assessment of his own cardiac risks and any steps that could have been taken to reduce these. Had this been arranged, this may have confirmed or excluded this potential concern for Clive and his family.”

The expert Cardiologist also noted that as someone with a learning disability, Clive may not have been able to describe the symptoms he was experiencing with accuracy, and doctors should have lowered their threshold of suspicion and conducted further investigations. He concluded: “The interpretation of symptoms in individuals such as Clive may be challenging. In such cases, erring on the side of caution – even if only to exclude a cardiological diagnosis – would represent a more secure and reassuring approach.”

Although the specific cardiac event itself was deemed by the Cardiologist to be unpredictable, the underlying heart conditions that Clive did have, as described by the Pathologist, and for which Clive was receiving some medications (for example hypertension), do appear to have placed him at potentially higher risk in the event of a seizure. Furthermore, had Clive survived the cardiac event on the night he died, the Cardiologist confirmed that measures may have been put in place that could have reduced the risks going forward.

It was certainly the case that Clive reported having chest pain on many occasions. Put together with other references in his care records about his inability to report pain accurately, our view is that it was inappropriate to dismiss his reports of chest pain without more investigation.

When Clive attended an orthopaedic clinic for a fractured shoulder in 2015, the clinician reported that Clive was not able to describe the pain he was experiencing or directly relate his responses to the injury. In our view, Clive’s complaints of chest pain should have been investigated in conjunction with utilising the pain tools available, which have been designed to assist staff in assessing pain in individuals with a learning disability. Failure to respond to the reports of pain and dismissing them as part and parcel of someone’s behaviour and learning disability is a form of diagnostic overshadowing and can result in significant medical symptoms being overlooked, sometimes with fatal consequences.

## Obesity

Clive’s weight increased by 27kg in the last eight months of his life following his admission to Cedar Vale. In May 2016, Clive weighed 86kg. This rose to 93kg in August, 100kg in October and 113kg in January 2017. Poor diet and a failure of staff to encourage and enable physical exercise were significant contributory factors.

Clive’s health promotion care plan at Cedar Vale stated that he was at increased risk of developing physical health problems such as cardiovascular disease and set out the importance of “closely monitoring changes in his physical, mental and behavioural state by his staff team to ensure that any possible variations in his physical health and wellbeing are spotted and acted upon”.

The review finds that the variation in Clive’s weight wasn’t picked up and acted upon in a timely way as required by his care plan. It was first properly highlighted as an issue at Clive’s annual health check in November 2016, and subsequently discussed at his multi-disciplinary team meeting in December 2016 where it was noted that: “Clive is currently refusing *the* majority of meals choosing to eat a lot of cheese. He buys a lot of unhealthy snacks and survives on these the majority of the time. His snacks are kept in his room and he is constantly eating. MDT to advise on how to support Clive without taking away his right to choose.” The MDT also suggest at this point that contact be made with Clive’s GP, dietitian, and community nurse for support. It is unclear if this was actioned before his death a month later.

The lack of timely attention to Clive’s weight gain also meant that the risks associated with it were not effectively considered, escalated and acted upon, in practice. Clive’s weight gain not only increased his cardiac risk, but also affected his sleep apnoea and increased his risk of seizures.

Records also indicate that staff failed to proactively encourage or take action to promote healthy eating and considered that Clive had the capacity to make informed decisions around the



consequences of poor diet. An action to undertake a capacity assessment was suggested at the December MDT meeting, despite records indicating that Clive was assessed as lacking capacity in making decisions relating to his health promotion plan on 6 October 2016.

We know that Clive was a good runner, and loved walking and being outdoors. Clive's care plan states that Clive "will engage in a wide variety of activities if supported and motivated by his supporting staff". However, at Cedar Vale, he had limited opportunity and was rarely encouraged to undertake physical exercise. Section 17 leave enabled Clive to take a short walk to the local shop on a weekly basis, but observation records indicate he spent the vast majority of his time either watching TV or sleeping. This is also likely to have had a considerable impact on Clive's weight gain.

### Anti-psychotic medication

Clive's family explained that when he was prescribed Olanzapine, an anti-psychotic drug, it had a negative impact on him. They said he was taken off Olanzapine at St Andrew's Hospital for a period of time. Clive's family believe that he should not have been taking Olanzapine, and feel they were not engaged effectively in the decisions around this and should have been better involved in decisions to re-prescribe it.

The expert Pharmacist reviewed the records and reported that these show that Olanzapine was recommended by the Consultant Neurologist (2011) for anxiety and to control problem behaviours, but not specifically for psychosis. The expert Pharmacist explained that Olanzapine was discontinued in August 2015 due to hyponatraemia<sup>51</sup>. He explained that it was then re-prescribed in January 2016 after it was reported that Clive had been responding to visual hallucinations, was intermittently aggressive towards staff and expressed 'paranoid ideation' (feelings of suspiciousness and paranoia) towards them. The hyponatraemia did not change significantly during the period Clive was not on Olanzapine. In fact, the sodium level slowly returned to the lower level of normal without any obvious intervention.

In December 2016, Clive's MDT at Cedar Vale also records concerns about his mental state – that he was "presenting with clouded consciousness and characteristics of acute confusional state". In addition to exploring the relationship of this to Clive's seizures, it was proposed that Olanzapine should be reduced. This was not implemented before Clive's death in January 2017.

The expert Pharmacist described the side effects identified by the British National Formulary (BNF) that Olanzapine may cause dizziness, feeling unsteady, or having trouble keeping your balance, restlessness, unusual behaviour, depression, difficulty falling asleep or staying asleep, weakness, difficulty walking, constipation, weight gain, dry mouth, pain in arms, legs, back, or joints, breast enlargement or discharge, decreased sexual ability. He explained that it is difficult to know to what extent Clive suffered from any of these side effects, but as he suffered from constipation and was classified as obese, "Olanzapine may not have been a good choice of anti-psychotic".

The expert Pharmacist explained that Olanzapine is not a standard treatment for general anxiety disorder. The treatments recommended for general anxiety disorder by NICE (the National Institute for Health and Care Excellence)<sup>52</sup> are primarily psychological therapies with educational support. He concluded by noting that: "If medication treatment is advocated, the usual first and second line treatments are the selective serotonin reuptake inhibitors (SSRI) anti-

<sup>51</sup> **Hyponatraemia** is an uncommon side effect that can result in low sodium concentration in the blood. It can cause headaches, nausea, poor balance and decreased ability to think. ([Definition source: National Center for Biotechnology Information](#))

<sup>52</sup> [NICE \(2019\), Generalised anxiety disorder and panic disorder in adults: management Clinical guideline \[CG113\], Published date: 26 January 2011, Last updated: 26 July 2019](#)



depressants. However, in the case of Clive, such treatments would not be recommended as they were likely to worsen his epilepsy.”

The expert Pharmacist, who reviewed all the medications Clive was prescribed for this review, commented that in general it was not clear how the impact of the range of medications prescribed was monitored and reviewed. This is of serious concern, and more comprehensive steps should have been taken to review the risks and benefits of the combination of prescribed drugs at regular intervals – in line with NICE Guidance and best practice outlined in the STOMP campaign (stopping over-medication of people with a learning disability or autism)<sup>53</sup>.

## Dental problems

Following Clive’s tumour surgery in 1998, Clive lost his teeth and wore dentures. This was in part due to side effects of the tumour, but also in part due to poor oversight and care of teeth, which resulted in Clive’s teeth rotting. Clive was also on some medications that are associated with dental decay. These may have contributed to this, but there should have been careful oversight and support to reduce these risks.

## Hearing impairment

In December 2014, while at St Andrew’s Hospital, the speech and language therapy (SALT) team carried out a hearing assessment on Clive. It showed a degree of hearing loss which was broadly similar in both ears. The loss was noted to be “quite significant across the speech frequencies and would be sufficient to cause him some difficulties distinguishing conversational speech particularly in the presence of background noise”. A referral to audiology was made at Northampton General Hospital for Clive to be fitted with hearing aids. Clive also needed a build-up of ear wax to be removed before hearing aids could be fitted. Clive’s family reported that he was due to receive hearing aids while at St Andrew’s Hospital, but this did not happen.

Clive registered with a new GP practice in May 2016 when he moved to Cedar Vale. The GP made a referral to a clinic in the Queen’s Medical Centre for ear wax removal on 26 May 2016, and there is a record that the ear wax was successfully removed. It is not clear if this was the first appointment offered or if Clive had not attended others, but it was an unacceptably long time to wait for a condition that was causing additional hearing loss.

Clive’s nursing assessment at Cedar Vale recorded that “Clive can struggle to understand other people at times due to his reduced hearing”. However, despite the family reporting repeatedly chasing them for Clive to have his hearing aids fitted, he was without hearing aids until his death. Clive’s family explained that the staff at Cedar Vale suggested that he would refuse or choose not to do certain things, such as attend the audiology appointment or cooperate with the tests – and suggested that he may not tolerate hearing aids if he had them. However, Clive’s family were clear that this was not the case, as Clive had always been compliant with medication and treatment in other settings. In their view, Cedar Vale failed to recognise the support Clive needed in attending hospital appointments and failed to make reasonable adjustments that would have supported him to access the audiology appointments when he needed to.

Clive’s hearing loss would have had a direct impact on Clive’s understanding of speech and his ability to interact and cooperate with the people around him.

## Speech, understanding and dysphagia (swallowing difficulties)

The records show that Clive had his speech and language skills assessed by speech and language therapy teams at St George’s Hospital in 2011 and subsequently at Cedar Vale in 2016, and that he regularly was seen by SALT teams throughout – in particular for his

<sup>53</sup> [‘Stopping over medication of people with a learning disability, autism or both \(STOMP\)’, NHS England](#)

dysphagia. They found that Clive had generally good communication skills, but required people to use short and clear sentences to aid his understanding. There is little evidence to suggest how any communication assessments were applied in practice when assessing his capacity to make decisions, how they were used to interact with Clive on a day-to-day basis or support him to manage his behaviour.

The SALT team at St George's Hospital assessed Clive after there had been several incidents of choking. They established that Clive was at risk of choking – especially during seizure activity when there was an increased risk of aspirating food into his lungs. They recommended certain types of softer food, chopped into smaller pieces, and that he was to be supervised while eating at all times. Clive's fluid intake could not exceed 1.5 litres a day, and needed to be strictly monitored to manage sodium levels, which could trigger seizures. Clive's dysphagia and fluid intake was kept under review at St George's and St Andrew's hospitals.

Following Clive's admission to Cedar Vale, an initial dysphagia assessment was carried out on 6 May 2016 by a speech and language therapist, which failed to recognise Clive's well-established risk of choking. Clive's nursing assessment on 18 January 2017 states that Clive did not have any difficulties chewing or swallowing, and does not make any reference to historic assessments or recognise the risk. There does not appear to be an emergency protocol to manage choking should it have occurred. This placed Clive at further risk of harm.

### **Pain following orthopaedic surgery**

While at St Andrew's Hospital, Clive was involved in an incident with another patient in which his ankle was injured, and he was transferred to Northampton General Hospital. Clive's ankle was found to be fractured, and he underwent surgery to repair it that involved the insertion of a metal plate. Clive's 12-week review report on 15 August 2016 at Cedar Vale notes that he attended the fracture clinic during the time his leg was in plaster, and that his mobility was assessed by an occupational therapist who provided a wheelchair and other aids. However, following the removal of the cast, care records note that Clive continued to complain of pain in his ankle, especially at night or after walking into the village. They said Clive relied heavily on pain relief medication on a regular basis.

Clive's family say that he told them that this continued to cause him pain. It was considered that a shift in the plate may have created another fracture. His family report that this was not followed up or addressed by Cedar Vale. The care records show that Clive was prescribed painkillers, but there was no evidence in the records of any further referrals for investigation or that any of the well-established pain tools designed for using with people with a learning disability were used to assess the degree of pain Clive was likely to be experiencing.

## Conclusions and recommendations: Health inequalities

The health inequalities experienced by Clive are ones commonly experienced by people with a learning disability. They are extremely well documented<sup>54</sup>, and all specialist health providers should be fully aware of these and the duties they have in promoting good physical and mental health. It is extremely concerning that some of the specialist health facilities in which Clive was placed appear to have lacked knowledge, understanding or regard for the importance of taking steps to actively address the health inequalities of the people they care for.

**Diagnostic overshadowing resulted in missed opportunities to investigate fully serious health conditions for Clive including underlying heart conditions. This, together with the compounding influence of other factors that were present at his time of death, placed Clive at increased risk of sudden death.**

Health Education England and the Academy of Medical Royal Colleges should seek to ensure that clinical training for all medical, nursing and care staff highlights the issues of diagnostic overshadowing in people with a learning disability who may be unable to express themselves in traditional verbal communication.

NHS trusts, GP practices and independent care providers (specialist hospital and community) should provide training to raise awareness of the issues of diagnostic overshadowing for people with a learning disability who may be unable to express themselves in traditional verbal communication and equip them to detect early signs of deterioration using tools and approaches for the management of deterioration.

Regional NHSE/I teams should work with health and care systems at a local level to ensure there is a clear focus on diagnostic overshadowing across primary, secondary and community care services and monitor progress.

**Clive's CPAP machine was left in disrepair for at least seven weeks prior to Clive's death and this 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.**

Care providers must act in line with the guidance<sup>55</sup> that makes it clear that it is their responsibility to maintain and use medical equipment as prescribed.

Commissioners of care provision (specialist hospital and community) must assure themselves in the regular oversight of care, that individuals have access to and are supported to use medical equipment as prescribed.

The Care Quality Commission must ensure that services are compliant with Regulation 15 (that the equipment that is used to deliver care and treatment is clean, suitable for the intended purpose, maintained, stored securely and used properly) and take regulatory action if these standards are not met.

**In general, it was not clear how the impact of the range of medications prescribed for Clive was consistently monitored and reviewed.**

Clinical commissioning groups should work with general practices, consultants and clinicians involved in prescribing medication to ensure regular reviews are taken to monitor the risks and benefits of the combination of prescribed drugs at regular intervals in line

<sup>54</sup> ['Improving health of people with a learning disability', NHS England](#)

<sup>55</sup> ['Equipment Standards, Guidance and Legislation', EBME \(28 September 2019\)](#)

with NICE Guidance and best practice outlined in the STOMP campaign (stopping over-medication of people with a learning disability or autism)<sup>56</sup>.

The barriers that Clive experienced to accessing healthcare were not always fully understood, and reasonable adjustments were not always made by health and care providers. There were occasions when Clive was not supported to access important health appointments on the basis that he had refused to go, despite advice and support offered by his family to do so – such as audiology appointments to be fitted for hearing aids.

**Commissioners of care provision (health and social care) must require care providers (specialist hospitals and community) to fulfil their duties under the Equality Act 2010 to make reasonable adjustments and meet their duties under the Mental Capacity Act 2005.**

Commissioners should actively monitor that reasonable adjustments are being made through the regular review of care for individuals and through contract compliance processes. Providers should be held accountable where this is not met.

Primary, secondary, tertiary and independent care providers (specialist hospital and community) should provide training to raise awareness of reasonable adjustments and ensure staff are equipped to support people with a learning disability, autism or both to access services effectively.

Regional NHSE/I teams should work with health and care systems at a local level to assure that there is a clear focus on awareness and implementation of reasonable adjustments across primary, secondary and community care services and monitor progress.

**In some cases, care providers failed to promote good physical health for Clive and failed to recognise and manage the associated risks. For example, Clive gained over four stone in weight in the last eight months of his life as a result of poor diet and a failure to encourage and enable physical exercise. This affected his quality of life and increased his risk of premature death.**

Commissioners (health and social care) should ensure that processes in place to oversee and review care such as Care and Treatment Reviews<sup>57</sup> (CTRs) are actively reviewing the physical healthcare and meaningful engagement of individuals including monitoring weight gain and physical activity.

The CQC should fulfil its regulatory responsibility to ensure that mental health hospital settings and specialist hospitals for people with a learning disability, autism or both provide good physical healthcare, and meaningful engagement and activity in line with established clinical standards and best practice.

As the professional medical body at the forefront of setting and raising standards in psychiatry, the Royal College of Psychiatrists should consider how it can raise awareness and help to improve standards of physical healthcare and meaningful engagement of people with learning disability in specialist hospitals.

<sup>56</sup> [‘Stopping over medication of people with a learning disability, autism or both \(STOMP\)’, NHS England](#)

<sup>57</sup> <https://www.england.nhs.uk/learning-disabilities/care/ctr/>



## 4. Commissioning and oversight

**Commissioning organisations responsible for commissioning and monitoring Clive's care did not always place him in settings that could meet his needs and did not sufficiently monitor the quality of care he received. On some occasions, this placed him at risk of harm.**

Clive had a very clear unfaltering ambition to settle in a home of his own in Lichfield close to his family. He did not want to live alone, and was happy to share with one or two other people. He wanted to go on holiday, go to college and eventually find a job. When he was unwell, he wanted to have staff with him for help. He loved nature and wanted to visit the countryside. Instead, Clive found himself moving through an extraordinary number of care settings from the age of 18, much of this time at a great distance from his family home and often moving reactively at short notice. The services supporting Clive were not always equipped to effectively understand and support the complexity of his needs, particularly in relation to his epilepsy and behaviour. As a result, his experience of care was often poor.

In the absence of the right support in the community, Clive ended up detained in hospital for what was intended to be a brief period of assessment and treatment. Once inside, there was no clear focus on achieving a discharge option for Clive. Ineffective assessment and treatment and the impact of institutionalisation moved him further away from that ambition and he ended up spending 10 years of his life detained in hospital. The introduction of the Transforming Care Programme triggered action to move Clive out of an inappropriate hospital setting and started the process to transition him back into the community in the last year of his life, but the challenges of finding appropriate care within the community remained. The option to look at a bespoke personalised package of care was not readily available for Clive, who sadly passed away before his ambition to live in a home of his own close to his family could be realised.

Poor oversight and continuity of care by health and social care commissioners underpinned Clive's experience of care. This was particularly evident when Clive was living out of area. The review recognises that the way in which health and social care commissioners, social workers, community nurses, and other specialist community health clinicians who come together to coordinate and oversee care is considerably more developed now. However, Clive's journey underlines the critical importance of effective care coordination and oversight at every level to ensure quality of care for, and safety of, every individual.

### School years

Although Clive's epilepsy disrupted his schooling, Clive was able to participate in mainstream education up until the age of 11 with the support of an inclusive primary school. In 1980, Clive moved to a mainstream secondary school that proved to be very difficult for him primarily because he could not safely use stairs due to the level of seizures he was experiencing. Clive's family shared that the school did not feel able to safely support Clive, and as a result he was excluded from this school and wider mainstream education at the end of that year. Staffordshire County Council supported Clive to move to a specialist school for children with physical disabilities which the family describe as 'phenomenal'.

Leaving school, no transition planning had been considered and Clive struggled to find colleges locally or regionally at the time willing to accept him due to his epilepsy. Staffordshire County Council found a place for Clive at Lingfield Hospital School, a specialist college in Surrey for young people with a learning disability and epilepsy. Clive was very close to his family, and although they were reluctant to see him move so far away, they were supportive at the time feeling that this would be start of a lifelong journey for him to pursue his ambitions.

## Community residential care (1989–2007)

On leaving college and up until 2007, Clive's care continued to be largely coordinated and overseen by Staffordshire County Council.

Staffordshire County Council supported Clive to move to a specialist residential care setting providing education and therapeutic support for people with a learning disability and autism. It was seen to be a centre of excellence for epilepsy. Clive's physical and mental health started to deteriorate significantly while at this setting, and the family raised serious concerns to the provider and the council about neglect and the quality of care. Clive was urgently moved from this setting in 1993 following police and safeguarding investigations into alleged sexual abuse of Clive by a member of staff (see Section 7, part 7: Safeguarding).

In March 1993 (at the age of 23), Clive was quickly moved on a safeguarding order to the Sands Centre in Rugby. This was a small six-bed house that the family describe as a 'home environment' and one of the few places Clive really enjoyed. Clive enrolled in a local college for art, he was gardening and wanted to get a job. The family describe the staff as skilled and passionate, and say they treated Clive with kindness and respect. "Clive had a good quality of life there, and thought this could be his home." However, seizure activity continued to develop, and Clive was suffering injuries such that providers felt that they could not keep him safe. Clive was there for seven months before being moved again.

In November 1993, Clive moved to Richmond Mews, a specialist care home with nursing provision for people with a learning disability in Stoke-on-Trent. Clive's seizure activity and health rapidly deteriorated during his time there. The family describe him returning to the days of his early years, bedridden in a dark room, suffering from severe pain in his head, vomiting and not being able to stand up. Clinicians struggled to stabilise Clive's epilepsy and records indicate that he became increasingly bad-tempered and sometimes displayed aggressive behaviour.

The family raised lots of concerns at the time about seizure activity and health deterioration, which they felt were not taken seriously. Following an MRI scan in 1997, it was revealed that Clive had a slow-growing brain tumour which was removed through surgery in February 1998.

Frustrated and concerned by the quality of care Clive had received, the family moved him back home to live with his mum in 1998 – with support from learning disability day services and respite services. Responsibility for Clive's care continued to be principally held by Staffordshire County Council, but with increased involvement from health commissioners (previously South Staffordshire Health Authority, which subsequently became South Staffordshire Primary Care Trust in 2002) for a contribution to funding of some community packages.

Between 1998 and 2007, while Clive was living closer to home, continuity of care improved and Clive was better supported by a lead social worker (Staffordshire County Council) and complex care nurse (Staffordshire Primary Care Trust) working in partnership. The family recall the positive impact the complex care nurse had in terms of continuity of care for Clive, making a positive attempt to get to know Clive and understand his epilepsy and behaviour. She spent time observing, tracking, and monitoring Clive's seizures and mood changes, and played a liaison role, working with his Epilepsy Consultant at the Queen Elizabeth Hospital and other professionals. This highlights the importance of having a named professional who was able to build a relationship with Clive and his family. This was lacking for the large part of Clive's life, particularly during his time living out of area.

Clive was very close to his mum, but being back at home and living together was not always easy. As the years progressed, the family witnessed Clive starting to get increasingly frustrated and angry. The family recall that "Clive was angry at all that had happened to him and all those around him". It got to a point where Clive's mum could no longer manage at home, and in

August 2000 (at the age of 30), Clive was temporarily moved to a large residential home for people with a learning disability. It was acknowledged that the environment wasn't necessarily appropriate for Clive's needs, but was a temporary fix while a more permanent solution was sought.

Funding from South Staffordshire Health Authority for one-to-one support was secured for Clive at this time, due to the increase in behaviours deemed to be challenging and the epilepsy support that Clive required. Clive had been restricted in previous placements due to the availability of staff to support him when out and about in the community, so this one-to-one support helped reduce Clive's seizures and gave him a lot more freedom.

Between 2000 and 2007, Clive moved through a further five residential care settings. Only one was able to effectively support Clive and became a place he felt at home. The family describe there being "no effective long-term planning for Clive, just short-term solutions to his care".

In March 2002, Clive was admitted to the psychiatric unit at Stonefield House, St George's Hospital for 12 weeks as a result of threatening behaviour. The behavioural deterioration was thought to be secondary to an anti-epileptic drug, Topiramate. A psychological assessment at the time also raised that Clive presented with significant memory impairment and highlighted that Clive had "difficulty with retaining and recalling verbal information and this may lead to a high degree of confusion and anxiety".

Following the 12-week assessment at the psychiatric unit, Clive was moved to Suttons Drive in Great Barr in late 2002. This was a small residential home for people with a learning disability offering rehabilitation. Clive lived here with five others and four full-time carers. The family speak highly of this placement. It was small and homely. Clive felt settled, considered it a permanent home and was able to make his own choices. The provision was on church grounds, allowing Clive to go to Sunday Service every week, which he valued as a spiritual person. Clive attended college, held a work placement at a garden centre and was happy. Clive had friends, had days out, garden parties and gatherings that the family would join.

Records indicate that Clive's behaviour was more settled while he was here. The family report that staff had the right skills to manage epilepsy and support behaviour, and so could provide Clive with a good quality of life. The family felt engaged and considered themselves 'a part of the team'. This experience demonstrates that it was possible to get the care right. However, in 2006 there was a dispute between Staffordshire Primary Care Trust (PCT) and Walsall PCT around the funding of package which fell across commissioning boundaries and the family report that Clive's time there was brought to an abrupt end.

## **Crisis support (2006/07)**

It is unclear how consistently local learning disability teams were involved in providing support to Clive, or whether they would have had the infrastructure to support him. What we do know, as a result of the work undertaken to strengthen community teams since Winterbourne View, is that in 2007, very few areas had services akin to enhanced/intensive support teams.

There were some consistent issues arising across care settings relating to behaviours deemed to be challenging, the triggers and responses. Staff did not always recognise these or know how to manage and support Clive's behaviour and reported being unclear about the underlying causes and its potential relationship to epilepsy. Earlier and more comprehensive assessment of Clive's behaviour and the development of a positive behavioural support plan may have better equipped staff to understand and support Clive and prevent escalation.

Clive's detention in 2007 followed incidents that took place in a residential care home in Nottingham that Clive had been residing in since 2006. Clive's family reported that the "authoritarian behavioural programme" instituted at this placement created a "hostile"



environment and served to increase Clive's anxiety and challenging behaviour. They raised concerns with local authority commissioners that Clive was required to earn rewards, which included visits to see his family, and that he was also routinely forced to eat in his room having not earned the reward to eat with others in the dining room.

The family recall that, at the point of admission, there were no alternative options available to them. At the point of crisis, had there been alternative options for Clive to safely support him, detention may have been avoided.

## **Detention in specialist hospitals (2007–17)**

In 2007, Clive was detained under Section 3 of the Mental Health Act (1983) and admitted to Stonefield House, a secure rehabilitation unit at St George's Hospital for a short period of assessment. The reason for admission is reported as a result of Clive's episodic challenging behaviour: "Stonefield House was considered in view of his episodic challenging behaviour and the associated risks he posed to others and himself." With no alternative options, the family were initially accepting of the admission to Stonefield House on a temporary basis, with the expectation it would keep him safe and serve as an opportunity for full assessment of his needs to get the future longer-term community placement right.

Following Clive's admission to St George's Hospital in 2007 and up until his death in 2017, responsibility for oversight and care coordination was principally led by health commissioners. NHS Stafford and Surrounds Clinical Commissioning Group (CCG) became the funding authority and responsible commissioner. Once Clive had been transferred into hospital, the family felt that Stafford and Surrounds CCG and Staffordshire County Council relinquished and passed on their responsibility for the oversight of Clive's care to inpatient providers.

The detailed records available from Clive's time in hospital indicate very little oversight or involvement from local authority or health commissioners prior to the introduction of the Transforming Care Programme in 2015. Before this, there is also little evidence of the health and social care commissioners actively planning to support Clive's discharge from hospital. The pattern of out of area placements and fragmented continuity of support meant that professionals did not know Clive very well and this hindered planning, arranging, and developing personalised local solutions.

Beyond the annual Care Programme Approach (CPA) meetings, there is little evidence of any external scrutiny or assurances being sought in relation to the quality of care or the effectiveness of assessment and treatment by health and social care commissioners. On at least one occasion, there was no external representation at the annual CPA meeting from health or social care commissioners. The only involvement of Staffordshire County Council appears to have been limited to the provision of social circumstances reports for mental health tribunals. These reports were authored by different social workers who had little or no contact with Clive and relied heavily on historical information and past social circumstance reports.

We know that good discharge planning begins at the point of admission. We know that successful discharge planning is a culmination of efforts from both inpatient and community multi-disciplinary team (MDT) members working in a synchronised way and in parallel with active treatment. In Clive's experience, it wasn't until 2011 – four years after his admission – that discharge planning was first considered and this process was almost entirely led by the inpatient provider, St George's Hospital.

Initial discharge planning records from St George's Hospital indicate that Clive needed a small, homely environment. However, their assessment that Clive's behaviour was firmly linked to his epilepsy took away the option for a move back into the community: "It is now unlikely that his challenging behaviour will be substantially modified such that his needs can be met outside a specialist inpatient setting."



There was no evidence to suggest that inpatient providers were being challenged by health or social care commissioners to think creatively about how Clive's needs might be met in a community setting, nor mobilising the local teams in Staffordshire to lead and support that planning. The community social work role (in providing social circumstance reports) and health commissioners appear to have accepted the prevailing clinical view that Clive needed to be in hospital. There does not appear to be any critical challenge of whether the acquired brain injury unit at St Andrew's Hospital, which Clive was transferred to in 2012, was appropriate. In 2016, the Transforming Care team (SSSFT) went on to accept that it was not the right environment for him.

Clive was transferred to St Andrew's Hospital in 2012 and remained there for four years despite serious concerns and complaints raised by his family that it was an inappropriate environment and about the quality of care. There is no evidence of any proactive consideration of discharge planning by the provider prior to November 2014 when health commissioners started to initiate discussions about discharge. CPA meetings briefly note that "there were no clear pathways identified for Clive following treatment and that a social care assessment would be needed to identify his support needs when the time came".

Having reviewed Clive's care records, the health and social care expert commissioner concluded: "The complexity of Clive's needs, particularly his epilepsy, came to define him. The absence of external professionals working together with the inpatient team with a clear goal to plan Clive's discharge, allowed that view of him to become normalised and therefore distance further, a life in his own home, close to his family."

## **The Staffordshire Transforming Care Partnership (TCP) (2015–17)**

Records from Clive's CPA meeting in January 2015 show that Clive was visited in November 2014 by a complex care nurse to discuss with him and his MDT at St Andrew's Hospital "needs and requirement needed for Clive to move onto a residential home specific to his needs". The notes record the family's wish that Clive should not be moved into another hospital environment. This was the first time since Clive's admission to St Andrew's Hospital that discharge from hospital was considered.

In February 2015, Clive was referred by Stafford and Surrounds CCG to the Specialist Adult Community Learning Disabilities Team for a review of his care as part of the Transforming Care Programme. The outcome was that Clive was "ready for discharge and should be supported to return to South Staffordshire to live close to his family and relatives". St Andrew's Hospital was asked to formulate a service specification for Clive, which was completed in March 2015.

In June 2015, South Staffordshire and Shropshire Healthcare NHS Foundation Trust (SSSFT) Intensive Support Service organised a meeting with Clive and his family to work with them to develop Clive's person specification and establish the kind of environment and support he would need to live safely in the community. Clive's history, likes, strengths, dreams and fears were mapped out alongside what a 'good life' would look like for him. This was shared at Clive's CPA meeting on 20 July 2015. The family report that, at the time, "they were promised the world", but quickly became frustrated with the lack of progress that followed.

At the end of 2015, the newly established Transforming Care team (SSSFT) commissioned by Stafford and Surrounds CCG became responsible for Clive's discharge planning. The Transforming Care Partnership team was commissioned "to monitor the quality of placements on behalf of the health commissioner, and in the longer term to work with service providers to identify a long-term placement which enabled Clive to achieve maximum independence". The team was comprised of a Transforming Care Lead, two nurses and administration staff, who we understand were responsible for supporting 14 out of area patients, including Clive, to leave

hospital and return closer to home. Clive's care was coordinated and overseen by SSSFT on behalf of Stafford and Surrounds CCG from 2015 up until his death.

Clive's initial Care and Treatment Review (CTR) in March 2016 was the first time that Stafford and Surrounds CCG commissioners, the Transforming Care team, the inpatient MDT and an independent Expert by Experience came together to review Clive's care. This provided a level of oversight and independent scrutiny that had been needed throughout Clive's time in hospital. It was the view of those engaged in the CTR that Clive was not ready to move into the community at that point in time due the length of time he had spent in hospital, the impact of institutionalisation, and the failure to prepare him for the community. Therefore, a further interim assessment and treatment unit was sought to enable transition.

The specification for an interim assessment and treatment unit developed by the TCP team was the first example of a person-centred plan identified in Clive's records, and provided a good outline of the sort of support he would require. Expert review advises that a more detailed focus on the skills that care staff needed and the day-to day support that Clive would require would have strengthened the process. Despite good efforts being made with the development of the person-centred specification at this point, 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.

The specification advised that: "It is essential new providers are aware of his care needs and work in collaboration with his current provider to enable a smooth transition." However, in practice there was limited collaboration between St Andrew's Hospital and Cedar Vale in transitioning Clive, particularly as he was in Northampton General prior to the move. Members of the MDT at Cedar Vale attended in person, and Clive's commissioners and family attended by telephone, a pre-discharge planning meeting that took place at St Andrew's Hospital on 26 April 2016. St Andrew's Hospital sent 22 documents to Cedar Vale and the commissioners, following this meeting. St Andrew's also sent Cedar Vale an updated four-page discharge summary, which was received the day before Clive's admission. Seizure data for the last year was also sent by St Andrew's Hospital to Cedar Vale and the commissioners on 20 April 2016, but this does not appear to have been recorded or acted upon.

To support the transition the TCP team and the family, concerned about the risks in relation Clive's epilepsy and sleep apnoea, sought assurances from the provider in relation to the epilepsy expertise of staff. They commissioned one-to-one observation levels and also provided training to care staff on the use of Clive's CPAP machine, which he used to help him breathe while sleeping at night.

Following Clive's transfer to Cedar Vale in May 2016, there was also a greater degree of oversight by the TCP team, with regular visits to see Clive and check on his care. A partial quality review was completed, which did not identify any concerns overall and the team were actively involved in the key milestone reviews. However, the review of Clive's epilepsy care by the Epilepsy Specialist Nurse advising this review questions the extent to which the quality review effectively assessed epilepsy care (see Section 7, part 2: Epilepsy) and picked up on family concerns. The TCP team continued to work with the family and Cedar Vale to plan for and progress Clive's discharge. Records show that Cedar Vale responded to requests from the TCP team to prepare documentation for Clive's discharge, such as a personal health budget plan. There was a marked increase in access to the community for Clive, which demonstrated positive risk taking, but evidence of any wider strategy and interventions to prepare Clive for the community was lacking.

The TCP team established a Family and Carers Forum for Clive's family and two other families. The Forum was seen to be a valued mechanism through which the families were able to support each other and work collaboratively to progress the discharge process. Individually they

had each struggled for many years to be heard, and the Forum helped to ensure that their voices were heard and that professionals were held accountable for the promises made and delays incurred. The families wrote to the Chief Executive of Stafford and Surrounds CCG in May 2016 to express their concerns about the difficulties they had experienced with the current system to support their loved ones to secure a tenancy and 'home for life' of their own in the community. The families have continued to support each other and remain in contact today.

The opportunity to establish a bespoke provision for Clive with two other individuals with similar needs was explored, but this fell through and the model to identify a placement through a large-scale procurement exercise was pursued. This process, although extensive and lengthy, served to take the family back to the same pool of providers that had already been identified, who were unable to meet Clive's needs. The process was abandoned and, frustrated and anxious about further delays to the process, the family enquired about the option for them to develop a bespoke package of support for Clive using personalised budgets.

Insight into this process was provided by members of the Transforming Care team at the time. The TCP Programme Lead at South Staffordshire and Shropshire Healthcare NHS Foundation Trust (SSSFT) at the time spoke of the enormous frustration she experienced in endeavouring to support Clive towards having a place to call home in the community. She explained that she and the small TCP team were not effectively equipped or supported to take on the role. Staff described the structural challenges they faced including the way in which the TCP team had been commissioned. Stafford and Surrounds CCG had "commissioned the SSSFT clinical team to work with the current providers, social workers and the family members to support future placements on behalf of the CCG; however, as the commissioning function remained with the CCG, the TCP Team only managed part of the process i.e. the assessment and care coordination elements which related directly to the individuals."

This effectively separated commissioners from working with the families to co-design the service specifications and from the critical procurement stages. Documents indicate that the Transforming Care team became the intermediary, with the decision-making responsibilities and power remaining with the CCG. This resulted in a lack of effective governance structures in place to sign off on plans and associated costs, a lack of capacity and insufficient clinical and managerial support. Underdeveloped community services and a lack of appropriate care provision were also critical issues.

We heard that the pressure from NHS England nationally placed on the CCG and TCP team at the time to reduce the number of inpatients quickly had led to what was described as a "toxic environment". The TCP Programme Lead (SSSFT) commented that she knew that Clive's family felt that she had let him down, but that she had been trying her best in a system that simply was not working. She concluded by telling us that hearing of his death was a key reason that she ended her nursing career and took up another occupation.

## Conclusions and recommendations: Commissioning and oversight

**Person-centred care planning:** There is limited evidence of any formal person-centred care planning for Clive before the Staffordshire Transforming Care team became involved in 2015/16.

Commissioners (health and social care) should ensure that all staff who are involved in developing community-based packages of support are skilled in person-centred life planning. Where achieving discharge is proving difficult, they should appoint an independent life planner.

**Commissioning capacity and capability:** Commissioning organisations responsible for commissioning and monitoring Clive's care did not always place him in settings that could meet his needs and did not sufficiently monitor the quality of care he received. On some occasions, this placed him at risk of harm. The role of a commissioner for people with a learning disability is complex, necessitating strategic and person-centred capabilities. Developing good, sustainable outcomes for people with a learning disability requires a well-supported, integrated and sufficiently resourced commissioning workforce, with access to external specialist expertise where it is unavailable within their organisations.

NHSEI National Learning Disability & Autism Programme should review existing quality standards for the commissioning of care for people with a learning disability, autism or both and consider whether further quality standards need developing or strengthening.

Commissioning organisations (health and social care) should ensure that local commissioners of care for people with a learning disability, autism or both have the skills and expertise to commission care for people with complex health needs that is safe, effective, and personalised to meet individual needs. The new [Level 5 accredited qualification: commissioning for wellbeing with a learning disability and autism focus](#) can support with this and should be prioritised by health and care systems for commissioner development.

NHSE/I National Learning Disability & Autism Programme should review the uptake of the Level 5 accredited qualification: commissioning for wellbeing with a learning disability and autism focus and put in place measure to improve uptake where this is required.

Commissioning organisations (health and social care) should ensure skilled supervision and development for commissioners which reflects the complexity of their roles.

Commissioning organisations (health and social care) should review the capacity of teams responsible for the commissioning and coordination of care for people with a learning disability at a local level to ensure they are sufficiently structured, equipped and resourced to meet local needs.

**Procurement:** The procurement process limited the options for Clive rather than enabling commissioners to build a tailored package of support around him to meet his needs. The opportunities for Clive were restricted by the view that he could only be supported in specific specialised care settings and the limited availability of these services. There needs to be a fundamental shift in the way services are designed and procured to meet the needs of people such as Clive.

CCGs and local authorities should ensure that commissioners and community learning disability teams are encouraged and supported to develop tailored packages of care around individuals' needs.



CCGs and local authorities should critically review the effectiveness of existing procurement options/frameworks to meet the needs of people with a learning disability and autism in their area.

**Oversight and accountability: There was ineffective oversight and accountability for the quality of Clive's care overall that failed to address experiences of poor care and led to a prolonged detention of nearly 10 years.**

Health and social care commissioners should ensure that individuals, whether they are in specialist hospital settings, living in residential care, with family or independently, have a named care coordinator who has statutory responsibility for consistently maintaining contact with them and their family.

**Preventing hospital admission: At the point of Clive's crisis, there should have been alternative options to safely support Clive so that detention may have been avoided.**

CCGs should ensure that there is intensive crisis support available at a local level for people with a learning disability to prevent them from reaching crisis and support them when they do.

CCGs should actively work with carers and care providers to identify and provide support to those at risk of admission at the earliest opportunity possible.

NHSE/I National Learning Disability & Autism Programme should oversee and seek assurance that crisis support is available and effective.

**Discharge planning: There was no concerted discharge planning to move Clive out of hospital until 2015/16 – some nine years after his detention. There was no clear evidence that commissioners were driving the hospitals to focus on treating and preparing Clive for community living. This prolonged detention decreased his chances of successful discharge.**

Commissioners (health and social care) must ensure discharge planning starts before admission, without fail, with a clear timeframe in place. Discharge planning must involve all relevant sectors, who will be involved in providing support in the community working together to think critically about how individuals can be supported to live fulfilling lives in the community.

## 5. Specialist hospitals – care and treatment

**There was a lack of good quality care and treatment for Clive’s presenting needs, including NICE-compliant approaches to behaviour analysis and intervention, in the specialist hospitals he was detained. For the most part, responsible clinicians overseeing Clive’s inpatient care did not see life outside of hospital as an option for Clive and failed to pursue a timely discharge for him. Alongside the impact of institutionalisation, this moved him further away from living the life he wanted and resulted in an unnecessarily prolonged detention in hospital of nearly 10 years.**

In July 2007, Clive was detained under Section 3 of the Mental Health Act (MHA) and admitted to a specialist hospital for a short period of assessment and treatment but ended up spending 10 years of his life detained in three different specialist hospitals.

Supported by an expert Consultant Nurse Approved Clinician, this review has sought to understand why Clive ended up detained in hospital for so long. We have looked specifically at:

- The appropriateness of Clive’s ongoing detention and whether it could have been ended sooner
- Clive’s experience of being detained in specialist hospitals
- Whether the specific hospitals in which Clive was detained were appropriate to his needs
- The effectiveness of the assessment, treatment, rehabilitation and continuing healthcare Clive received.

### Stonefield House/ Milford House, St George’s Hospital: July 2007 – July 2012

Reports indicate that Clive initially settled in reasonably well at Stonefield House – participating in a structured programme of activities including painting, music and gardening. Clive also accessed community leave on a weekly basis, usually to the local shops, and would visit his mother monthly. His treatment plan comprised: “achieving optimum control of seizures, ongoing review of medication, one-to-one observations due to risk of injury from seizures, positive participation in activities, monitoring of physical health and support for healthy diet and exercise”.

Records indicate a good focus on the management of Clive’s physical health overall, although there is acknowledgment that staff struggled to understand and manage Clive’s epilepsy. The Responsible Clinician (RC) at St George’s was firmly of the view that Clive’s behavioural presentation was directly linked to his epilepsy and was keen to better control his epilepsy. The RC actively sought the help of a Specialist Epilepsy Consultant in 2010, who played an important role in the ongoing management of Clive’s epilepsy.

However, as time progressed Clive started to become more unsettled in the environment. By 2010, Clive’s family were deeply unhappy with Clive’s ongoing detention and very concerned that the environment was inappropriate and causing Clive’s physical and mental health to deteriorate. Clive was frustrated at the length of stay, and wanted to live in a flat closer to home. Records show he was spending more time in bed and became less engaged in activities. His level and frequency of aggression had increased, as well as his levels of self-harm. The family challenged the lack of progress in Clive’s presentation and wanted to see him discharged. They were specifically concerned that Stonefield House did not have specialist epilepsy expertise, and that Clive was not getting the level of epilepsy care he needed. This was acknowledged at Clive’s CPA meeting in October 2010, where the RC noted that “there was nowhere at the time that could manage both the epilepsy and challenging behaviour”.

In terms of supporting and managing Clive’s behaviour, the expert clinical review of records finds that a largely medical and containment approach to behaviour was taken. There was a

heavy emphasis on behaviour arising from epilepsy and while it is recognised that the situation was complex, the focus on epilepsy meant that wider functions of behaviour were not effectively considered. Medical reports note: “It is the belief that if Clive’s seizure activity is effectively managed then his challenging behaviour will reduce. This formulation is supported by...neuropsychiatrist<sup>58</sup> and Clive’s behaviour can vary throughout the day. This is in relation to his epilepsy and acquired brain injury.”<sup>59</sup>

Certainly, there is no evidence of consideration being given to the impact of earlier trauma as set out in later sections of this report. The expert clinical view is that: “This over emphasis on epilepsy being the cause resulted in diagnostic overshadowing and prevented the team from considering how Clive’s environment, detention in hospital, relationship with peers etc was impacting upon him.”

There are a number of documents that detail the nature of the behavioural presentation described as challenging and refer to the need to use the ‘Staircase Model’<sup>60</sup> in addition to restrictive measures such as one-to-one continuous observations and physical intervention. The expert assessment is that while the ‘Staircase Model’, which was in place at St George’s at the time of Clive’s admission, may have been a useful approach for generic staff in managing patients with a learning disability in conflict resolution, it had insufficient depth and breadth for a specialist hospital unit. The Consultant Nurse Approved Clinician who provided the expert advice to the review concluded: “It is likely that it is due to the absence of functional analysis, fully applied behavioural analysis and a positive behaviour support approach that the service has relied upon more restrictive measures.”

In Clive’s 2011 nursing reports, the RC recognises that St George’s Hospital was not an appropriate environment for him and that he required a more long-term, homely environment to support his needs. She stated that: “Clive has been at Stonefield house for almost four years. Clive is aware that this is not a permanent home, and this causes him anxiety and insecurity. Now the assessment process is drawing to a close, we have a clear picture of Clive’s needs and what care package needs to be in place to meet these. We now need to begin the process of finding Clive a long-term placement that meets his complex health needs and behavioural needs as well as providing him a homely environment that provides him with the underpinning principles of normalisation.”

In addition to several other hospital providers, a referral was made to the Acquired Brain Injury (ABI) Unit at St Andrew’s Hospital (Northampton) in October 2011 and was accepted. It is not clear from the records why Clive’s diagnosis of an acquired brain injury above other needs became more prominent to the specification for a future placement, or why the ABI Unit at St Andrew’s Hospital, a large hospital environment, became the preferred option for Clive – particularly given the specification for a homely environment.

Clive continued to be detained under Section 3 of the MHA throughout his time at Stonefield House. Ongoing annual detention renewal meetings and Mental Health Tribunals accepted reports from professionals that Clive continued to require assessment and treatment within a specialised hospital environment based on his complex epilepsy and assumed related challenging behaviour. Clive’s RC wrote: “It is now unlikely that his challenging behaviour will be substantially modified such that his needs can be met outside a specialist inpatient setting.”

<sup>58</sup> Stonefield House, Developmental Neurosciences and Learning Disabilities Directorate Medical Report, Midlands Partnership Foundation Trust Medical Record (2011)

<sup>59</sup> Stonefield House, Developmental Neurosciences and Learning Disabilities Directorate Medical Report, Midlands Partnership Foundation Trust Medical Record (2011)

<sup>60</sup> The **Staircase Model** was referenced in Clive’s case notes. It appeared to be a behaviour model where rewards and sanctions were issued in response to the behaviour exhibited.

Records show that Clive was consistently accessing the community on most days, without any issues indicating that a community option was certainly a possibility to be explored. This was a missed opportunity for Clive to leave hospital and detention, which could have been achieved had there been greater multi-disciplinary scrutiny of Clive's needs and what he wanted, and how this could be achieved in the least restrictive way.

## St Andrew's Hospital, Northampton: July 2012 – May 2016

In July 2012 (at the age of 42), Clive was admitted from St George's Hospital to the Tallis unit at St Andrew's Hospital in Northampton. This is a secure, 14-bed inpatient care and rehabilitation unit for adult men who have an acquired/traumatic brain injury and who experience complex behavioural, psychiatric, and emotional difficulties.

Clive initially made good progress here. Following admission, he underwent a series of neuropsychological assessments in 2012 and was supported by a neuro-behavioural programme designed to promote positive behaviour through structured feedback and rewards. His first CPA meeting in November 2012 summarised: "Clive's assessments have been completed and they did not show anything unexpected. Clive's IQ was tested in 2005 and the outcome this time is consistent with the previous result. It is recommended that he uses assistive technology, along with diaries and boards. The structure, groups and programmes on the ward also suppress his behaviours. There was some physical aggression towards others earlier on in his admission, but this is no longer seen. Clive consistently receives 90% of the points in his reinforcer programme and responds well to positive feedback."

The expert clinical view is that: "The time on Tallis Ward is important to the understanding of Clive's behavioural presentation. In a number of areas, there is information that clearly links behaviour to seizure activity and whilst this may be the case; this information from the CPA token economy programme<sup>61</sup> and engagement in preferred activity demonstrates that a large proportion of the behavioural presentation is linked to other functions, which are likely to be amenable to change were a structured applied behavioural analysis approach to be taken."

This initial progress led to him being transferred on 16 April 2013 within St Andrew's Hospital internal care pathway to Berkeley Close, a secure step-down unit offering slow stream rehabilitation. Berkeley Close was a community-based admission unit located in a quiet residential area. Shortly after the move, Clive presented with prolonged seizures and was admitted to the Northampton General Hospital for emergency care provision. On his return from hospital, Clive was moved from Berkeley Close to another ward, having been there just nine weeks, due to the safety risks posed by being on the first floor with no lift. Had reasonable adjustments been made, this may have enabled Clive to continue this pathway and supported an earlier discharge.

Clive was moved to the Walton Ward, a large, locked ward with 24-hour specialist nursing support, care and supervision<sup>61</sup> for men with acquired brain injury. On the ward, Clive continued with the neuro-behavioural programme and his behaviour was closely monitored and recorded. Clive had the opportunity to join ward-based activity groups which included mindfulness psychology review sessions, a mindfulness meditation group, creative arts, reminiscence therapy and a music group. Records note that Clive was encouraged to attend group sessions, but rarely attended by this point.

<sup>61</sup> **A token economy** is a system for providing positive reinforcement by giving tokens/points for completing tasks or behaving in desired ways. Tokens are then exchanged for a desired item.



Records indicate that Clive struggled with the large ward environment and found the move difficult. His overall levels of anxiety and aggression increased around this time, but settled sufficiently that on 5 September 2013, Clive's detention status was rescinded and he temporarily became an informal patient with his care provided under Section 5 of the Mental Capacity Act (MCA). Records from Clive's second CPA meeting in October 2013 describe his mental health as showing "intermittent irritable episodes which were secondary to his unhappiness being on Walton Ward, but stable overall".

By early 2014, Clive's family observed a significant deterioration in his physical and mental health and raised concerns about his safety and quality of care with St Andrew's Hospital. Clive started to present with physical aggression against other people and self-harm. Behavioural analysis at the time, outlined in his annual CPA report (12 May 2014), records that "...aggression against self has remained relatively stable since the last review period. There has been an observable increase in incidents of non-cooperation and physical aggression against others." The report goes on to state: "the most common antecedent to Clive's aggression was during restraint/restrictive holds (39.1%); the second most common was verbal prompting (19.5%) ...verbal feedback and holding techniques were the most frequently observed interventions to manage Clive's aggression during the current review period."

Expert advice is that evidence suggests that behavioural analysis at this time focused largely on frequency and severity of behaviour, and there is no indication that a clear functional analysis or comprehensive assessment was undertaken at this point. The May 2014 CPA clearly highlights a link between the use of physical intervention and behaviour, with almost half of all incidents reported arising from restraint and restrictive holds – but does not go on to discuss how to break this perpetuating cycle. Clive's deterioration resulted in a higher degree of supervision of his daily routine; a Mental Health Act assessment was conducted, and he was placed back under Section 3 of the Mental Health Act on 29 May 2014.

The family reported that Clive did not cope well with the rigid routine of the ward, and a sample of observation records indicates he would spend large parts of the day alone in his room asleep. The family also explained that Clive struggled with the reduced frequency of visits home and limited access to community leave. His May 2014 CPA report notes he had visited his mother twice in the last six-month review period (previously at St George's Hospital he had visited once a month), and records show he was frustrated with not being able to get out and do more. The family told us that they raised concerns about Clive's deterioration and self-harm within St Andrew's Hospital, but struggled to get Clive timely support or to be heard (see Section 7, part 7: Safeguarding). Had their concerns about self-harm been listened to and supported earlier, they believe this would have prevented Clive's resection.

In July 2014, Clive moved again with the patient group and staff to the Althorp Ward, in a different building within the grounds of St Andrew's Hospital, due to a service reconfiguration exercise. Clive found the move again to be stressful, but records note that there was an observed reduction in 'risk behaviours'. Clive's CPA review in December 2014 notes: "Clive says that he finds it difficult to live with so many other residents, saying that this can cause him to have seizures. Clive says he has nothing to do here like going to college like he has done previously. He says he finds it difficult not having day trips and has no holidays." Records indicate that he continued to be offered the opportunity to participate in a weekly breakfast club (attendance was variable due to him struggling to get up in the mornings) and had the opportunity to attend some group-based activities such as baking sessions.

Clive continued to be unhappy and disengaged at St Andrew's Hospital, and by July 2015 records show that "Clive's engagement in all therapeutic activity offered had reduced and the neuro behavioural programme appeared to have stopped being effective". In October 2015, Clive went on to disclose to his psychiatrist his experience of historic sexual abuse (see section on Safeguarding – allegation of sexual abuse).

In the last six months of Clive's time at St Andrew's Hospital, a number of interventions followed: Clive received a series of one-to-one sessions with his psychiatrist to help support him with the impact of historic trauma – this was one of the few occasions that Clive's trauma was acknowledged and support provided. Action was also proposed to identify new reinforcers, which included Skype calls with his father to improve his motivation and engagement; there was no evidence that this was trialled.

Clive also attended 15 out of 19 wider psychology sessions including four one-to-one sessions, four mindfulness meditation group sessions, three creative arts group sessions, three memory lane group sessions and one music group session. Clive's CPA report documents: "Overall, Clive has had good engagement throughout sessions, however it has been noticed that during the mindfulness group Clive's engagement deteriorates. This usually leads to Clive leaving the session. At times in group sessions, Clive appeared easily distractible and attempted to talk over people about unrelated topics; however, responded well to guidance to focus on the topic under discussion."

An action for psychology to work with Clive and his team to complete a formulation to understand the function of his behaviour, emotions and thoughts and also to produce a positive behavioural support plan is evidenced in his January 2016 Care Plan.

The review recognises that there is evidence of a summary formulation functional analysis completed in April 2016 and stress anxiety test in December 2015, a series of behavioural assessments on admission in 2012 and ongoing detailed charting of behavioural incidents throughout. However, it is the expert clinical view that evidence suggests that the required level of functional analysis and positive behavioural support was insufficiently detailed and focused for much of Clive's time at St Andrew's Hospital. The Consultant Nurse Approved Clinician suggests that: "records appear to indicate a primarily reactive approach that relied on physical intervention for a good proportion of the response, despite this causing a number of the behavioural events that they then refer to in their rationale for the physical intervention being maintained."

While we can clearly see that psychological sessions were offered to Clive, as documented above, particularly more tailored to his needs in the last six months of his stay, it is the expert clinical view that for someone who stayed for so long in one hospital, that the psychological therapy offered to Clive for much of his time at St Andrew's Hospital was not adequate.

The first time that discharge for Clive from St Andrew's Hospital was considered was in November 2014 when he was visited by a complex care nurse to discuss with him and his inpatient MDT "needs and requirement needed for Clive to move onto a residential home specific to his needs". The notes record the family's wish that Clive should not be moved into another hospital environment.

In February 2015, Clive was referred by Stafford and Surrounds CCG to the Specialist Adult Community Learning Disabilities Team for a review of his care as part of the Transforming Care Programme. The outcome was that Clive was "ready for discharge and should be supported to return to South Staffordshire to live close to his family and relatives" (see section on Commissioning and oversight).

In January 2016, the newly appointed Transforming Care (TC) Lead responsible for Clive's discharge met with Clive's mother, father and sister for the first time. Records note that they were very upset and angry, having felt they had previously been unheard when raising concerns. The family reported that they were worried about the amount of time he spent in his room, stating that he didn't appear to be encouraged to engage in activities or leave the grounds; they reported that he often looked "unkempt" and was still in his pyjamas in the late afternoon. They were anxious regarding behaviours that could lead to self-harm as they felt he

was often left in his room with little supervision. Clive's sister had stated that his condition had significantly deteriorated since being on Althorp Ward, and she was anxious to see him moved.

On 25 January 2016, the TC Lead met with Clive's resident social worker at St Andrew's Hospital who provided guided access to Clive's electronic records and showed the TC Lead around the ward. Records show that the social worker looked back over Clive's records from the previous eight weeks and it was noted that Clive had accessed the community three times during this period: once to attend the dentist, once to attend the optician and one episode of home leave. The only other time Clive had left the ward in the last three-month period was to visit the on-site café.

Clive's social worker reported that he refused to engage in physiotherapy or occupational therapy, but that he did see the psychologist. It was noted that Althorp being a brain injury ward "made it difficult to meet the needs of a learning disability client as the ward routines don't allow flexibility". Queries were also raised about the management of Clive's epilepsy, seizure monitoring and management of sleep apnoea. Concerns were raised about the approach to behavioural support: records indicated there was a positive behavioural support plan in place, but the TC Lead felt that staff were not sufficiently aware of the plan and had not received training regarding positive behavioural support.

Clive's social worker at St Andrew's Hospital agreed to look into these matters, and they were followed up at a Care and Treatment Review for Clive in March 2016 attended by representatives from Stafford and Surrounds CCG, the TC team and Clive's inpatient MDT. At this meeting, a detailed discussion about Clive's care and treatment took place. This included confirmation about access to the community: Clive's inpatient MDT stated that Clive was accessing the hospital grounds once a week, the community once a month and visits home quarterly. It also suggested that better understanding was needed of why Clive did not participate in activities, noting that Clive worked much better on a one-to-one basis and that a more personalised plan of activities responding to his needs was required. The meeting also discussed the risks associated with Clive's epilepsy and sleep apnoea. It was collectively agreed that the placement for Clive on the Althorp Ward was not suitable and plans were progressed to identify new provision as soon as possible (see Section 7, part 4: Commissioning and oversight).

On 15 April 2016, Clive fractured his ankle in two places and was admitted to Northampton General Hospital where he was kept in for surgery for three weeks. The fracture happened following an incident with another service user. Clive's family were insistent that Clive should not be returned to the Althorp Ward at St Andrew's Hospital due to concerns at the time, and plans were put in place for Clive to transition directly to Cedar Vale in Nottingham.

### **Cedar Vale, Nottingham (May 2016 – January 2017)**

On 4 May 2016, Clive was transferred from Northampton General Hospital to Cedar Vale in Nottingham, an assessment and treatment unit for men living with a learning disability, autism and complex needs. This was intended to be a short-term, interim placement offering rehabilitation support that could meet Clive's needs with a view to securing a bespoke package in the community in the future. Clive received one-to-one support in his own flat in a ground floor annexe with access to a garden and facilities in the main building.

The level of observation was initially budgeted to cover the first week to manage any risks with sleep apnoea in the transition period but was continued for the duration of Clive's time at Cedar Vale due to the recognised risks of him having a seizure while asleep and using the CPAP machine.

Records indicate that Clive settled in well at the outset. A care and treatment review took place on 17 May 2016 attended by Clive, his family, the TCP team and the hospital MDT. Clive was



reported to have been very happy and engaging positively. Staff at Cedar Vale described him as “very charming with a huge amount of potential”. The occupational therapist recorded that Clive loved to visit the village every day and was enjoying pet therapy. He was recorded to be sleeping well and using his CPAP machine. The multi-disciplinary team at Cedar Vale were confident that Clive would be able to be discharged from his section and supported under deprivation of liberty safeguards in the coming weeks. Plans were thought to be moving ahead for Clive to be supported into the community.

Clive also underwent a programme of behavioural assessments following his admission to Cedar Vale, the outcome of which was reported at his 12-week review in August 2016. The expert clinical review identified evidence of a real improvement in Clive’s behavioural assessment at Cedar Vale. She noted that “a multi-elemental plan to support Clive using an applied behavioural analysis approach was in place. There was also a marked increase in access to the community through the use of section 17 leave. The very limited use of physical intervention and as required medication to sedate also provide an indication of Clive’s positive response to the application of applied behavioural analysis, the different environment and therapeutic milieu.”<sup>62</sup>

Records indicate the TCP team frequently visited and contacted the hospital to oversee his care and to work with the provider to plan for Clive’s discharge. In the main they were satisfied that Clive was receiving good quality care. However, despite a positive start, Clive’s family raised concerns that Cedar Vale lacked important information about Clive’s needs in the months that followed his admission. They were specifically worried about the care quality and management of Clive’s epilepsy and sleep apnoea, and raised concerns with the TCP team about Clive not wearing his protective helmet, the risks of moving Clive from the ground floor to the first floor, about restricted communication with Clive, and that staff were not sufficiently trained in managing epilepsy. Informed by expert advice, the review finds the quality of epilepsy care at Cedar Vale was lacking (see Section 7, part 2: Epilepsy and part 3: Health inequalities).

The records also show that, despite a positive start, a structured routine and engagement in meaningful activity petered out relatively quickly. Although recurring MDT meetings identified the need to improve Clive’s engagement in meaningful activity, the level of activities available to Clive appeared limited. Observation records and MDT notes indicate that as time progressed, Clive appeared to become increasingly disengaged and spent much of his time sleeping, watching TV or reading magazines (see Section 7, part 3: Health inequalities).

## Summary

In summary, the review finds that Clive did not need to be detained in hospital for 10 years, and that there were critical missed opportunities to discharge him from hospital and support him to live the life he wanted. He remained in hospital for so long, not because he needed a decade of ongoing assessment, treatment, rehabilitation and continuing healthcare, but fundamentally because:

- There was no clear multi-disciplinary focus and concerted planning to achieve a discharge option for Clive for eight out of those 10 years. It is the expert clinical view that “detention could have been ended sooner had there been changes to the nature of the care, support and treatment and engagement of a joint inpatient and community MDT who had a clear focus on achieving a discharge option for Clive to move to.”
- The care and treatment Clive received failed to effectively address his needs and prepare him for life outside of hospital. The complexity of Clive’s needs warranted a similar level of

<sup>62</sup> A **therapeutic milieu** is a structured environment that creates a safe, secure place for people who are in therapy. This milieu involves not just the provision of safe physical surroundings, but also of supportive therapists and staff. ([Definition source: Very Well Mind](#))



complexity to specialist health assessment and interventions. There was an absence of person-centred care planning and evidence points to a more medical, reactive and containment approach to behaviour. Limited formulation, often arising from the belief that Clive's behaviour was entirely linked to his epilepsy, prevented the full utilisation of person-centred planning and applied behavioural analysis and therefore limited any chance to obtain optimum change in behavioural presentation.

- There was an unchallenged view for nine out of those 10 years that Clive's needs could not be met outside of a hospital environment, which was not sufficiently questioned or scrutinised by inpatient providers or health and social care commissioners. There was a lack of documented positive risk testing and clear strategy to reduce restrictions, particularly physical intervention, to a level that could be replicated in the community. In some cases, Clive had very limited access to Section 17 leave during his detention. Additionally, the community care and support that Clive required outside of hospital was not readily available, which prevented responsible clinicians from feeling confident that Clive could be discharged safely within existing legal frameworks.
- The process for the renewal of detention was not always robust. The family sought to question the renewal of detention by hospital managers, but did not feel they had enough information or understanding about the process to do so. They were not always informed of hospital detention renewals and there was at least one occasion on which a decision to renew Clive's detention was confirmed on the basis that Clive had raised no objections without assessing his capacity to make that decision, although it is likely that he did not have the capacity to do so.

## Conclusions and recommendations: Specialist hospitals – care and treatment

The findings of this review echo issues raised in the CQC report ‘Out of Sight, Who Cares’ (2020)<sup>63</sup> in relation to care provided in specialist hospital settings, and emphasise the critical need for assurance at all levels that people with a learning disability who are admitted to assessment and treatment units and other specialist hospitals, receive high-quality, specialist care for short periods, which is focused on discharge.

**Commissioners of specialist hospital provision for people with a learning disability must ensure that:**

Before admission to hospital, people have assessments through community teams so that their needs are understood and they have clear and measurable objectives set for their admission to hospital and receive care in an appropriate environment.

On admission, further assessments take place, including for autism, sensory, mental health, physical health, trauma, learning disability and any other relevant assessments. This is to ensure that the objectives and care plans are meeting people’s needs. There must be a contract in place stating the timeframe for these assessments to take place.

All specialist inpatient units provide a therapeutic environment to enable the delivery of trauma-informed and person-centred care in line with existing evidence-based models. In particular, autistic people must be cared for in small person-centred units with the right sensory environment, as recommended by the National Institute for Health and Care Excellence (NICE).

Discharge planning must start before admission, without fail, with a clear timeframe in place. Discharge planning must involve all relevant sectors, who will be involved in providing support in the community.

There must be a named budget holder for the person’s care. Where a new placement is required to enable discharge, the named budget holder, which is likely to be a clinical commissioning group (CCG) or local authority, must be responsible for commissioning the identified requirements within an agreed timeframe.

There must be a named community health team lead and a named community social work team lead in addition to the inpatient team and any commissioning professionals for people with complex needs and their families.

There should be a check that families and advocates have full information regarding detention status and their rights and options under the relevant legal framework to enable them to adequately and effectively advocate for individuals – subject to detention under the Mental Health Act.

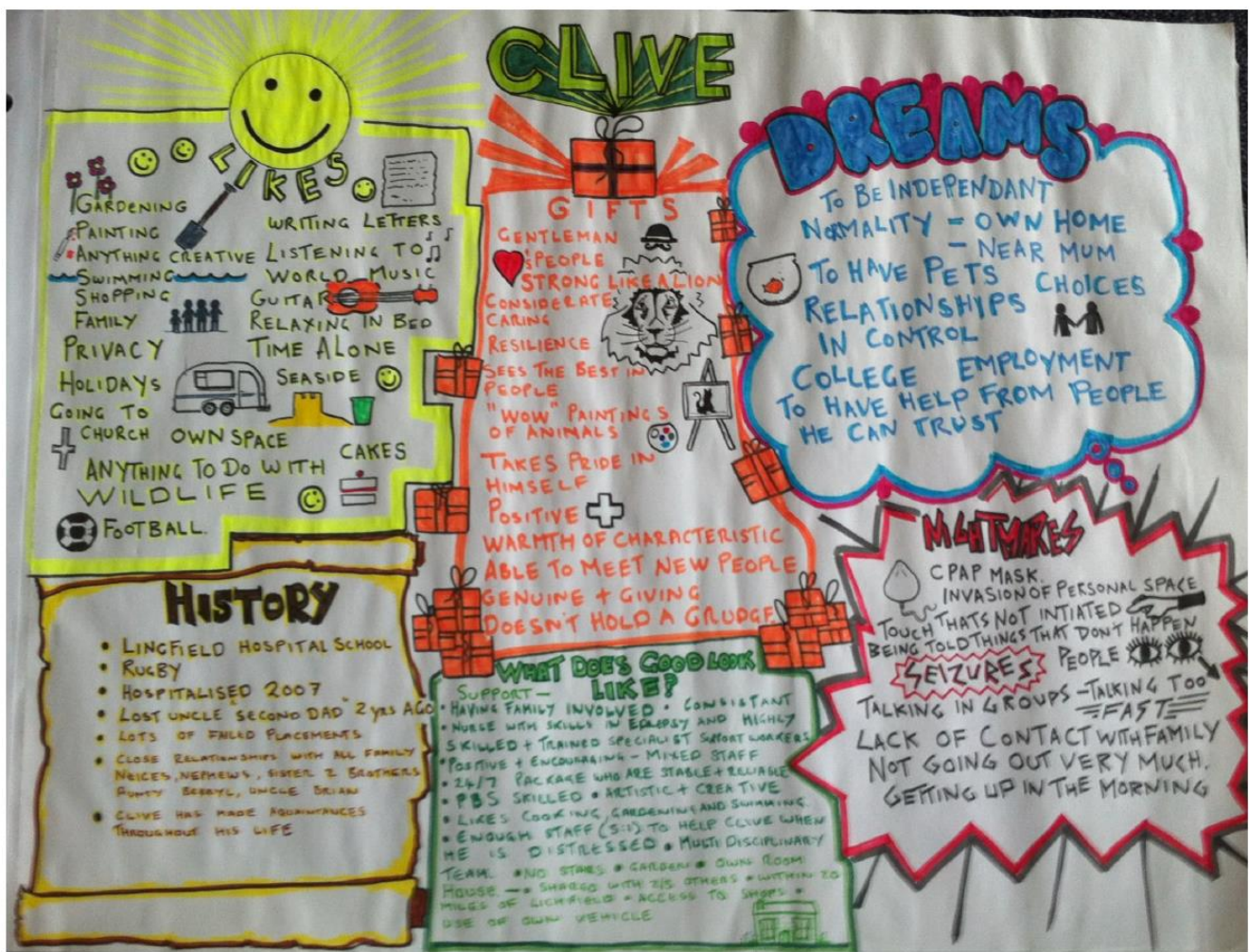
<sup>63</sup> [Care Quality Commission: Out of sight – who cares? \(2020\)](#)

## 6. The voices of Clive and his family

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.

Clive expressed himself verbally, artistically and on occasions by displaying behaviours that were deemed to be challenging. His family knew him for his positivity and his incredible ability to put the difficult things he experienced behind him and move on, hopeful of a better future. He had a clear and unwavering vision of his future – to have a home of his own, near his family, and a job – ideally in a garden centre. Staff who came to know him better described him as a gentleman and often remarked on his sense of fun (see Section 4: Pen portrait).

The best example of listening to Clive and mapping his views can be seen in the visual map below, which was developed with Clive and his family following the introduction of the Transforming Care team in 2015. The map describes well what had been consistently communicated over the years by Clive as his dreams and fears. It describes the kind of person he was and the things he enjoyed, such as gardening, painting, and going to church. It describes the dreams he had to live a happy everyday life, have a home of his own close to family, go to college and get a job. It also recognises the things he struggled with – getting up in the morning, not getting out very much, invasion of his personal space and touch that was not initiated.



Visual map describing what was important to Clive and the things he struggled with.

However, Clive's voice is distinctly lacking in the wealth of care records examined for this review. Clive was not routinely involved in meetings held to review and plan his care, or had



limited involvement in them. This appeared to be particularly the case during his time in specialist hospitals. Where attempts were made to engage his views, these sometimes appear tokenistic, and it is unclear how the views he communicated were acted upon. The attempts to manage Clive's epilepsy and behaviour deemed to be challenging meant that Clive's personality, hopes and dreams became secondary considerations.

- "The most important thing is getting my new address."
  - "I would like to go to college."
  - "I would like to go to town more."
  - "I wish I could go swimming."
  - "I would like to start baking in the afternoons."
  - "I don't enjoy staying in this place all the time"
- (St Andrew's Hospital, January 2016, and expressed previously).

What we can see widely recorded are examples of behaviours deemed to be challenging. In line with NICE Guidelines, the review recognises that behaviours deemed to be challenging usually serve a purpose for the individual and can be a means of communication. When unhappy or distressed, Clive would sometimes refuse to cooperate by not taking his medication, would damage equipment, or retreat to his room and refuse to engage. Despite the history of trauma and the complexity of the issues Clive faced, attempts were lacking to fully understand Clive's behaviour and what he was communicating.

The family report that their understanding and expertise in relation to Clive's needs was not consistently embraced to inform his care. They knew the triggers for Clive's epilepsy and situations that might make him anxious, and could recognise subtle signs that would indicate Clive's health was deteriorating.

They felt they were not proactively kept engaged with Clive's care. Often, Clive was living at a great distance from the family, and they worked hard to have sight of Clive's care. They were not always informed of incidents when Clive was taken into hospital. For example, the family were unaware for some time that Clive had been for tests and diagnosed with a brain tumour. The family proactively sought to be part of all of Clive's review meetings. They report that communication was particularly difficult at Clive's last hospital placement, Cedar Vale. Although they were welcome to attend, they were not invited to Clive's monthly review meetings, and they didn't feel that their concerns were taken seriously.

Clive's family recalled the many occasions in which they tried to communicate their concerns to services during Clive's lifetime. When trying to raise concerns, they found that they were often not listened to, and they felt that services labelled them as 'difficult'. Yet all their endeavours were focused on trying to ensure that Clive was safe and that plans were being made to help him achieve a good life in a home of his own.

When things went wrong, the family struggled to have their concerns and complaints heard. The record of concerns and complaints in different settings are extensive. In some cases, these were responded to by the provider via internal complaints processes, but often they were left frustrated and exhausted by a lack of response (see Section 7, part 7: Safeguarding).

Clive's family felt that the periods when they were properly listened to were rare. But when they were listened to, it resulted in them working as a team to support Clive. One such placement was Suttons Drive. In 2002, following an assessment at St George's psychiatric unit, commissioners sought to find a placement for Clive that would be able to manage his complex epilepsy, but in a more homely environment.

Suttons Drive was a residential home offering rehabilitation for people with learning disability, which Clive called home for over three years. The family speak highly of this placement. It was smaller and felt more homely. Clive felt settled and was able to make his own choices. The provision was on church grounds, allowing Clive to go to Sunday Service every week, which he



valued as a spiritual person. Clive attended college, held a work placement at a garden centre and was happy. Clive had friends, days out, garden parties and gatherings that the family would join. Records indicate that Clive's behaviour was more settled while here. The family report staff had the right skills to manage epilepsy and support behaviour and that the service provided Clive with good quality of life. The family felt engaged and considered themselves 'a part of the team'.

There are two other specific examples of support mechanisms which stand out in aiding Clive and his family to have their voices heard.

One is the support of an independent advocate. Clive had an independent advocate for over 10 years with whom he established a valued and trusting relationship from the late 1990s. The family describe the important role the advocate played in being a confidante to Clive, someone to talk to and share his personal thoughts with, independent of his family. Despite the immense value of this support to Clive, the family reported that she struggled to advocate for Clive in the coordination and oversight of his care and was not equipped to do so. There is reference to the need for Clive to have an advocate subsequently, but beyond brief appointments of advocates to support Clive through some of his mental health tribunals no further long-term advocates were appointed.

The second example is of a Family and Carers Forum established in May 2016 by the Transforming Care team for three families who were actively being supported by the team to discharge their loved ones into the community. The Forum, which met bi-monthly, was seen to be a valued mechanism through which the families were able to support each other and work collaboratively to progress the discharge process. Individually they had each struggled for many years to be heard, and the Forum provided an opportunity to ensure that their voices were heard and that professionals were held accountable for the promises made and delays incurred. The families have continued to support each other and remain in contact today.

## Conclusions and recommendations: The voices of Clive and his family

**Clive and his family should have been at the heart of the planning and delivery of his support, but their voices were often not valued or respected. Commissioners and providers should be required to involve families and carers in care planning, oversight and review.**

CCGs should ensure that there is a system in place which ensures that the views of families are incorporated and reviewed at every level of assurance.

CCGs should ensure that family and carer forums are available so that families can support each other in addressing their concerns with assurance that they will be listened and responded to.

CCGs should ensure access to good quality advocacy, which is an essential safeguard for people, especially people who are non-verbal or extremely mentally unwell, and may be unable to speak up for themselves.

NHSE/I should receive assurance from CCGs that providers of all commissioned services have robust family and patient involvement.

## 7. Safeguarding

**Clive was not always kept safe from harm while in the care of some care providers. The response to the many complaints and safeguarding alerts raised by the family and professionals were inadequate.**

The records show that numerous safeguarding referrals and complaints were made about the quality and safety of the care received by Clive across various settings and during his lifetime. Many of these were initiated by Clive's family and some were raised by commissioners or members of the Staffordshire Transforming Care team.

Clive's family have described how they struggled to have their concerns heard and the apparent failure to address these concerns by those with a statutory duty to protect Clive. The family continued in their attempts to raise their concerns. They did this via the complaints system of individual providers, by contacting the relevant Adult Safeguarding team, and by contacting the Care Quality Commission (CQC). They describe how much of the response took place "behind closed doors". They describe how the findings of investigations or reviews were not shared with them and rarely appeared to result in any action being taken.

One example of this is when Clive's family complained to Staffordshire County Council that, while Clive was at Burlington Villa in 2006/07, he was being routinely forced to eat in his room having not earned a reward to eat with others in the dining area. This was apparently part of a behaviour programme in which Clive had to earn rewards, which included visits to see his family. The family shared that they requested an advocate to support and protect Clive, but this was refused by the provider. The family described the environment as "hostile" and believe this impacted on the incident that led to his detention.

A further example was that, in July 2014, having struggled to have their concerns heard for some time, the family raised formal complaints with the provider, health commissioners and the CQC about the quality of care Clive was receiving at St Andrew's Hospital, Northampton. They were concerned that the placement was not appropriate and was causing Clive harm. The CQC responded in August 2014 advising the family that they did not take up individual complaints and recommended that they raised this directly with the provider (it is noted that prior to 1 April 2015, the CQC had no powers to conduct criminal investigations into specific incidents relating to the quality of care provided). It was not until the end of September 2014 that they received a formal response to their complaints.

The records show that it was not until a series of incidents in January 2016, and when the Transforming Care (TC) Lead from the South Staffordshire and Shropshire Healthcare NHS Foundation Trust became involved, that many of the concerns Clive's family had about the quality of care at St Andrew's Hospital appeared to be taken seriously.

On 19 January 2016, the TC Lead first met with Clive's mum, dad and sister for the first time. Records note that they were very upset and angry, having felt they had previously been unheard when raising concerns. The records note that the family were worried about the amount of time he spent in his room, stating that he didn't appear to be encouraged to engage in activities or leave the grounds; they reported that he often looked "unkempt" and was still in his pyjamas in the late afternoon.

The family reported that staff told Clive he was "brain damaged" and that staff tended not to listen to him. They reported that the words "brain damaged" had been repeated to the family by a member of staff. They were anxious regarding behaviours that could lead to self-harm as they felt he was often left in his room with little supervision.

Concerns were also raised about Clive's epilepsy management and delays in getting hearing aids for his assessed hearing difficulties. The family also recounted their relationship with St Andrew's Hospital and the difficulties in communicating with them or being heard. They stated

that St Andrew's Hospital had told their staff that they should no longer speak to the family and only doctors could speak to the family.

This build-up of concerns for the family culminated in the lodging of a formal adult safeguarding concern in March 2016 when the family reported finding Clive sleeping in his room in the middle of the day in an unkempt state, and without his CPAP machine. The family reported being told by staff that the machine was removed from the room as per the care plan to encourage him to leave his room. The family were concerned that Clive was being neglected and that the CPAP machine was being used in a punitive manner.

Clive's care plan confirms that Clive's machine was not to be left in his room during the day due to the risk of breakage and also to "encourage him not return to his room as per the programme until evening time". On 23 March 2016, case notes from Northamptonshire County Council show that a high-level, inter-agency concern was raised about the "ongoing lack of care to the extent that health and wellbeing could deteriorate significantly" and a safeguarding investigation was opened.

The safeguarding investigation that followed did not substantiate this, and the records show that St Andrew's Hospital obtained clinical guidance about the use of the CPAP machine due to the issue of Clive damaging it when he was upset. They were advised that Clive should have access to the CPAP machine at night and that it was not necessary for him to have access to it during the day unless he was sleeping for prolonged periods during the day. After Clive's family complained, St Andrew's Hospital consulted the respiratory team again and although it was confirmed that the CPAP machine was for night-time use, St Andrew's Hospital decided to leave it in his room and try other strategies to reduce the risk of Clive breaking it.

The TC Lead pursued these and other additional concerns about the quality of care with St Andrew's Hospital and at Clive's Care and Treatment Review (CTR) meeting in March 2016. Due to the level of concerns raised, the issues were also formally raised to the CQC by the TC Lead. The CTR meeting itemised these concerns and the TC Lead stated that "the priority is to look at the most suitable placement for Clive where Clive will feel safe". The record of this meeting also notes that the "Expert by Experience stated he agrees with the families concerns and he will push forward recommendations from this meeting".

In April 2015, Clive fractured his ankle during an incident with another patient, and was admitted to Northampton General Hospital. Clive's family refused to allow him to return to Althorp Ward at St Andrew's Hospital and, as there was no other appropriate accommodation available, arrangements were made to transition Clive to Cedar Vale.

At Cedar Vale, family concerns began to deepen soon after his transfer. By July 2016, they had started to raise serious concerns about the difficulty they had in reaching Clive on the phone, that he was not wearing his protective helmet and principally that staff were not appropriately trained in epilepsy – with some staff only having received epilepsy training online. Clive shared with his family, both verbally and in writing, incidents of concern. For example, on one occasion he described in a letter that he had been pushed to the floor by staff. Following Clive's death, an Adult Safeguarding Review was conducted into the concerns raised by his family about the quality of care he received at Cedar Vale (see Section 7, part 10: Investigations and reviews following Clive's death).

Clive's family raised many safeguarding alerts and quality concerns – too many to detail here – with adult safeguarding over his lifetime, only to find that usually the action taken was that the provider was asked to conduct an internal investigation themselves which concluded that the concerns they had raised were unsubstantiated. The process of adult safeguarding teams asking providers to complete the review, usually within 21 days, is standard. However, it is also an approach widely criticised by families who do not feel reassured that the often serious

matters they raise have been dealt with thoroughly or objectively, and often leaves them feeling highly concerned about the safety of a loved one.

Clive's family believe that there was an overall lack of knowledge and understanding of safeguarding duty at all levels and across organisations involved in Clive's care and safety, from the frontline staff through to the regulator. While Clive's family were relieved Clive had been moved from St Andrew's Hospital due to the care quality concerns they had raised, they strongly felt that more action should have been taken to ensure others did not experience the same poor care as they believed he did.

Clive's family also expressed their serious concerns about the Nottinghamshire Police response to the concerns they raised following Clive's death, after Cedar Vale staff were observed on CCTV footage repeatedly flashing a torch in Clive's face. In the course of this review, the police were asked to review this footage further. On review, they stated that the behaviour did not break safeguarding rules and therefore no investigation was needed.

The CQC's review of research evidence<sup>64</sup> to inform the second independent report of inspections and regulation of Whorlton Hall looked at the experience of families who suspected abuse of their loved ones. It identified that families often noticed the 'little things' such as sleep patterns or diet. It talked about the issues of mistrust between families and staff arising from poor communication and the process of raising concerns as being "complex, frustrating and lengthy, requiring much time and energy". Families felt that staff were often not responsive and were defensive when concerns were raised. These speak entirely to the experience that Clive's family shared with the agencies that reviewed his care and treatment both while he was alive and in the circumstances that led up to Clive's death.

## Conclusions and recommendations: Safeguarding

**The concerns and safeguarding alerts that Clive's family and professionals raised over the course of his journey through community and specialist hospital settings were not adequately responded to. In our view, these were missed opportunities to intervene. Had these matters been taken seriously, this may have altered the course of events that followed.**

Local authorities and CCGs should urgently review and ensure that adult safeguarding processes in place to protect people with a learning disability are robust and in line with national guidelines.

<sup>64</sup> [G. Murphy \(2020\) CQC inspections and regulation of Whorlton Hall: second independent report](#)



## 8. Safeguarding – allegation of sexual abuse

**The safeguarding response to the alleged sexual abuse Clive experienced over several years failed to protect him from further harm and may also have failed to protect others.**

Clive's family told us that, in his early 20s, he was sexually abused by a perpetrator who was a staff member at the care setting where Clive resided between 1989 and 1993. Clive's sister described how this had come to light after she had visited Clive and he had handed her a roll of film for development, something he quite often did as he was a keen photographer. The photographs included a series of indecent images of Clive. The family reported this to the local police and shared that there was an investigation into this alleged sexual assault in 1993. The family shared that Clive's records were found at the carer's home, for which he was arrested and charged with theft. However, the sexual assault appears not to have been pursued by the police, his family recalling that this was due to the fact that Clive had "shut down" and would not speak about what had occurred. The family also recall that they witnessed a dramatic change in his behaviour following this trauma and feel that it continued to affect him throughout his life. Clive was moved on to a new care setting as a result.

In 1998, Clive's family learned that the alleged perpetrator had followed Clive and had continued to visit him in the five years he spent at the subsequent placement – without their knowledge. By the time Clive moved home to live with his mother in March 1998, the perpetrator had established a relationship with Clive, and he considered him a friend. The family were left struggling to protect him from an individual they recognised as an abuser who had groomed Clive and exploited his position of power as a staff member. The family raised concerns about the behaviour of this man who claimed to be Clive's friend, and a case review was led by a social worker who confirmed he had no knowledge of the prior history. There appears, from the records, to have been confusion as to the nature of this relationship and a lack of clarity about how to respond by staff, police and social care professionals at this time. There were concerns about the potential risk posed to others.

On examining this issue with Staffordshire police, their records show that in 1999, the local police force had received information that Clive was a victim of serious sexual offences while a resident at the care setting involved and that police officers were asked to interview Clive; however, there is no record of any further action taken by them or via the adult safeguarding process at that time. There is also no evidence that appropriate steps were taken to assess Clive's mental capacity to consent to a sexual relationship, to involve an Independent Mental Capacity Advocate (IMCA), and only a brief series of psycho-sexual assessments sessions.

In 2011, Clive disclosed the details of this to one of his care workers at St George's Hospital, sharing details of the sexual encounters with the alleged perpetrator at his home. These were very detailed and explicit descriptions of what had occurred, and Clive also recognised that this should not have happened. Staff reported this to Staffordshire Police and a number of meetings were held with Clive, but no further action taken.

In 2015, Clive disclosed again instances of historic sexual abuse in some detail to a care worker at St Andrew's Hospital. Clive's psychologist notes that he "appears to internalise those events as if they were caused by his 'sex illness' and worries that they may happen again if he becomes unwell. Clive appears to be traumatised by those early life experiences."

Clive reported that he was continuing to experience dreams and nightmares, and asked for support with his anxiety. Clive specifically asked for help to address his worries about safety on the ward, around guidelines for staff to relate to him in ways that didn't bring up his trauma memories. He also said that he feared his dreams may come true and cause epileptic seizures.

Clive's psychologist arranged to meet with him for 12 sessions to: "discuss dreams and nightmares he was having daily; if unhappy about something on the ward, to talk through

solutions; look at ways to calm himself down and worry less about daily thoughts or events". He also agreed to provide guidelines to staff on ways to interact with Clive when he was presenting unwell and pass on information to Clive's social worker at St Andrew's Hospital.

Clive's psychiatrist discussed the disclosure with his family in order to obtain more information. Clive's mother shared her worries about Clive's vulnerability and the risk of self-harm and sought help to ensure Clive's health did not deteriorate. There is no evidence that this was referred as an appropriate safeguarding alert.

With the exception of action taken at St Andrew's Hospital in 2016, there is very little acknowledgement in care records of the trauma that Clive experienced or consideration of this in the assessment of his behaviour and development of support plans throughout his care journey. No connections are made between the alleged sexual abuse and identified incidents of sexually inappropriate behaviour or the impact of the trauma on Clive's behaviour, apart from a file note that records a discussion between the Cedar Vale psychologist and a doctor from St Andrew's Hospital where his previous sexual abuse is shared. The doctor states that there could be a link between Clive's expression of his sexuality, his behaviour and the abuse he experienced. There is no evidence that consideration was given to the use of trauma-informed approaches to supporting Clive or that he received therapeutic support in regard to the alleged abuse or the sudden loss of someone he thought he was in a relationship with for many years.

Based on this review and with expert opinion, it is reasonable to conclude that Clive was groomed and was the victim of sexual abuse by a perpetrator who followed him across a number of settings for several years. Notably, this review has seen no evidence that the safety of other people who will have been present at the time/location of these alleged incidents of abuse was considered, or evidence of any action taken to prevent further harms.

## Conclusion and recommendations: Safeguarding – allegation of sexual abuse

**Clive was not kept safe from harm, and it is probable that he experienced sexual abuse while in the care of some providers. The safeguarding and police response to this appears to be wholly inadequate. It is a matter of serious concern that this review has not been able to ascertain what safeguarding and police actions followed these serious incidents. These are serious matters and beyond the scope and expertise of this review.**

Staffordshire County Council and Cheshire East Council should jointly commission an independently chaired review of the safeguarding response to historic allegations of sexual abuse in 1993, when Clive was placed with a care provider within the Cheshire County Council geographical boundary. The review should explore the national legal framework and processes that were in place on each of the occasions (1993, 1999, 2011, 2015) when the alleged abuse was disclosed or concerns were raised by staff or family and the adequacy of the responses.

The review should specifically:

- Assess the adequacy of the investigations into sexual abuse over the years and confirm its outcome and actions taken.
- Review and take action in relation to the potential risk to others who came into contact with the suspected perpetrator at the care setting or elsewhere.
- Identify where opportunities for learning exist.

**There is very little acknowledgement in Clive's care records of the trauma that he experienced or consideration of these in the assessment of his behaviour and development of support plans throughout his care journey. There is no evidence that consideration was given to the use of trauma-informed approaches to supporting Clive.**

CCGs should ensure that the potential need for individuals to receive trauma-informed care is systematically built into the process for commissioning and oversight of care for people with a learning disability and autism in specialist hospital and community settings.

## 9. The night Clive died

**The emergency response by Cedar Vale staff on the night Clive died was limited, confused and chaotic and may further have reduced his chances of survival.**

The sequence of events leading up to Clive's death on 31 January 2017 has been the subject of close scrutiny in the reviews and inquest that followed. However, Clive's family have remained dissatisfied and have presented evidence that we have considered carefully in this review. During this review, we were given access to the audio recordings of the inquest, the evidence given by members of the Cedar Vale team who were present that evening, Cedar Vale CCTV footage, the audio recordings of the ambulance service who attended on the night Clive died, the internal investigation and safeguarding review conducted following his death, and the notes made in his care records.

### The hours before Clive died

First of all, Clive's family raised questions about the account given by staff of how he spent the hours leading up to the seizure and the cardiac event that followed. They believe that the events leading up to this were not as described by staff in the internal investigation and at the Inquest, believing that there was, in fact, an altercation with staff – one that led Clive to call his sister to ask for help, to leave a message for his father to call an ambulance and for him to start packing his suitcase and attempting to leave. This contrasts with the account his care team gave at the Inquest, describing him as having a calm evening and going to bed after having a drink of hot chocolate. Despite raising this with both the police and the Adult Safeguarding Team after Clive died, no action was taken to address these concerns (see Section 7, part 10: Investigations and reviews following Clive's death).

During this review, Clive's family shared CCTV footage, from three camera angles recorded in the hours leading up to his death. The Coroner had only requested that the police provided footage from the period of time (4:00am) when Clive was found to be having the seizure but not in the hours that preceded this. At our request, Nottinghamshire Police have now analysed this footage from 8:00pm onwards on the night of Clive's death, and have stated that they have not observed any staff behaviours that would identify as abuse or neglect or that would meet a criminal or safeguarding threshold.

However, the family remain concerned about an incident recorded in the footage at 8:31pm in which a care worker appears to be speaking with Clive from the open doorway to his room and flashes a torch light at him. The police have noted that the CCTV footage does specifically show one member of staff flashing her torch as she stands near Clive's room. It appears that there are approximately five flashes of the torch by this female. This appears unnecessary given the lighting is already on in the corridor and in Clive's room. Clive's family were very angry to see that this occurred and also concerned that this may have directly triggered the seizure.

While Clive did not, according to the Consultant Epileptologist, have a light-sensitive form of epilepsy, this is not something (given the level of training and expertise the staff team had) that the staff were likely to be aware of. In addition, this behaviour is very likely to have caused Clive distress – which the records show was a trigger for his seizures. There is no further evidence available on what effect this had on Clive, or if it may have contributed to the seizure which subsequently led to his death that night. However, the family clearly were concerned about what Clive had told them and what they had witnessed on the CCTV.

### Epilepsy rescue protocol

Most people's seizures last the same length of time each time they happen, and usually stop by themselves. However, sometimes seizures do not stop, or one seizure follows another without



the person recovering in between. When a seizure goes on for five minutes or more, it is called status epilepticus (or 'status' for short). Status during a tonic-clonic (convulsive) seizure is a medical emergency and needs urgent treatment with emergency medication.

An emergency rescue protocol was in place at Cedar Vale for Clive, which was developed shortly after Clive's arrival and subsequently reviewed. The protocol advised that an alarm must be pulled in the event of a seizure, 10mg of Buccal Midazolam should be administered in the event of three tonic-clonic seizures (less than five minutes) within a 24-hour period or if a single seizure continues for more than five minutes.

On the night that Clive died, the Coroner's inquest revealed some ambiguity about the timing and length of Clive's seizure. Clive's family also question the accuracy of the time when the seizure commenced, and as a result, we have given careful scrutiny to this. With assistance from the police, we have reviewed the CCTV footage. There is a mismatch between the timing of the seizure originally recorded by care staff and that of the CCTV footage, some of which can be attributed to inaccuracy of the CCTV clock, but not all.

The witness statement of the care worker first attending to Clive records two seizures, the first being under two minutes; however, the Cedar Vale records state there was one seizure of 20 seconds. We can also see from the CCTV footage that Clive was also already in a seizure when staff first entered the room and pressed the alarm to alert the on-call nurse, who arrived at least two minutes later and found Clive in a seizure.

We have spoken to the nurse on duty at the time ('N') who explained that the one-to-one staff member had pressed the nurse call button and she had heard it ringing 'at length' and with apparently no response (practice would be for staff to switch it off on arrival at the location). Eventually she started to walk towards Clive's room, and on arrival the one-to-one staff member had just pressed the emergency call button when she entered the room. On entering Clive's room, nurse N recalled that Clive was already having a seizure and that shortly after this, having taken his oxygen saturation levels in line with his rescue protocol, emergency services were called and cardiopulmonary resuscitation (CPR) commenced.

It therefore cannot be ruled out that Clive's seizure was of longer duration than was reported, or that it was the second of two seizures. We do know that the prescribed rescue medication, Buccal Midazolam, was not administered, and this raises questions about whether there was a missed opportunity for rescue medication to have been administered had there been two seizures or in fact one longer than three minutes, and about the potential impact this could have had on preventing Clive's death. This review has been unable to get to the bottom of these questions.

## Emergency response

Clive's family asked whether everything had been done correctly on the night Clive died, and raised concerns after they had listened to the ambulance call centre audio recordings and looked at the CCTV footage available for that period of the evening. Clive's family explained that when his care was commissioned at Cedar Vale, this was on the basis that he needed to occupy a ground-floor room with direct outside access to allow ease of access for emergency services in the event of a severe seizure, together with a profile bed to manage his epilepsy risks.

They explained that the Transforming Care commissioning lead had specifically commissioned the service on this basis, but did not intervene when Clive was moved to the first-floor room, with a low level window and, initially, without his specialist bed, creating further risks to Clive. In particular, it is their view that the move to the first-floor room delayed the arrival of the emergency services. Clive's family had also noted that at the time Clive died, Cedar Vale was

still registered under the name of Castlebeck, and they felt that this had added to the delays in the ambulance service locating the premises.

The audio recordings of the ambulance service shared with us by Clive's family provide the sequence of events that spans approximately three minutes in which the ambulance call centre cannot understand the staff member giving them the location address, suggest they call back, and, after a delay, a different staff member picks up the phone who then gives the number of the building, the location and the post code.

Just over nine minutes into the second call, the ambulance service ask if the building is a hospital, what it is called and again for the full address. The staff member says that it is called Cedar Vale. and the ambulance service ask if it is called 'Castlewood Care' and the staff member explains that it was known as this before. The ambulance service also asked for the name and age of the patient. The staff member says his name and that he is 60 years old, which is incorrect as Clive was 47 years old when he died. Eleven minutes into the call, a member of staff is asked to meet the ambulance crew at the door to let them in and guide them to the room.

It is difficult to ascertain how much this may have delayed the arrival of the ambulance service and any further delay in reaching the first-floor location of Clive's room. However, it is clear that valuable minutes were wasted. As already established, Clive's high level of risk of sudden death was not sufficiently understood by Cedar Vale – had it been, all staff would have been equipped with a clear emergency protocol (as described below), one that they would have practised and which would have included how to pass the critical address and patient details to the emergency services.

## Administration of CPR

Clive's family were particularly concerned about the administration of CPR. They had viewed the CCTV footage of the CPR attempt, and listened to the ambulance service audio recordings and told us that they believed that his life could have been saved at that point if the staff at Cedar Vale had administered the CPR in line with their first aid training.

The records and verbal evidence at the inquest show that, in line with the rescue protocol, Cedar Vale staff checked Clive's oxygen saturation levels, found that these had dipped and administered oxygen. They reported that initially the oxygen saturation level began to rise but then suddenly began to dip and this was why they called the emergency services. The ambulance service call centre then began to talk the staff through the actions to commence CPR and administer shocks with a defibrillator.

We asked the expert Cardiologist his opinion on the delivery of the CPR. He explained that, despite this being an NHS specialist service and although the team had received mandatory first aid training, it was not something that they were experienced in doing and it would not be reasonable to expect that their response would parallel that of an emergency department. Staff confirmed that this was the first occasion that they had attempted CPR and, from the evidence given at the inquest, they were clearly distressed by the experience.

In the view of the expert Cardiologist, the chances of the team succeeding at this point were more in line with community provided CPR and had approximately only a 9% chance of success. That said, it is evident from the audio recordings and CCTV footage that there was some panic, some minutes wasted in giving the ambulance service the correct address and admitting them to the building, further time wasted in locating the defibrillator and transferring Clive from the bed to the floor. Standard first aid training is to do so, but this had not happened until the Ambulance Call Centre had advised staff to do so.

We met with the CQC Inspector responsible for Cedar Vale to find out what first aid and emergency procedures should have been in place. The CQC Inspector explained that the CQC standard 12, a fundamental standard, was applicable. This states that: “The intention of this regulation is to prevent people from receiving unsafe care and treatment and prevent avoidable harm or risk of harm. Providers must assess the risks to people’s health and safety during any care or treatment and make sure that staff have the qualifications, competence, skills and experience to keep people safe.”

She went on to explain that the onus is on the provider to assure themselves and the CQC that the standard has been implemented appropriately. We asked the CQC Inspector what she would have expected to see in place. She explained that she would expect that all staff would have completed ‘basic life support training’. At the inquest, staff confirmed that they had received basic first aid training, and some staff had completed this via an online module. The CQC Inspector further explained that at least one member of staff on duty on the night Clive died should have been trained in ‘intermediate life support’. She explained that even if there had been a qualified nurse on site, as we know there was, that unless there were opportunities to practise using these skills, staff may have had difficulty implementing them. While it is apparent that the staff present that night could have done better, their response was likely to have been typical of people trained at a basic mandatory level of first aid with no previous experience of administering CPR.

The CQC Inspector also explained that in addition to training, she would expect to see that there were ‘incident management procedures’ in place that would contain detailed procedures about what to do in an emergency. These should include who would lead, clarity about the location of any equipment that was likely to be required, such as a defibrillator, the practicalities about getting equipment to the room, etc. In Clive’s case, this would also need to include the ongoing review of provision, maintenance and management of oxygen. SUDEP Action explained about the extensive research that has been done to look at the mechanisms that are occurring in the body when someone is having a life-threatening seizure and how there is a very small window of opportunity, approximately three minutes, to attempt to save the person’s life.

We have seen no evidence that a plan to respond to this life-threatening event was in place. We asked the CQC Inspector if she considered that the safety standards she would expect to see in place for Clive at Cedar Vale were met when she inspected Cedar Vale after Clive’s death. We also asked if the CQC were satisfied that there are adequate procedures in place for other people with epilepsy being cared for in that environment – especially as, at the time of Clive’s death, a larger proportion of the residents had epilepsy.

The CQC have been unable to provide further information, due to the notes taken at that time being archived, about how they reached their conclusions when they responded to the concerns raised by Clive’s family in their letter dated January 2020. This concluded that “although there were individual staff failures that sadly led to a delay in your son receiving medical attention”, there was “insufficient evidence of provider failure in this regard. As such we were not able to pursue criminal action against the provider and as you will know, we do not have the power to take action against the individual staff involved.” However, the CQC Inspector referred to the 2018 Cedar Vale inspection and explained that she was satisfied that there were good safety procedures in place at that time and that these are documented in her report.

We also consulted SUDEP Action who have extensive expertise in premature death associated with epilepsy in the wider population as well as those who have a learning disability. They explained that research<sup>65</sup> evidence supports that when services for people with a learning disability take a structured approach to managing the risks associated with epilepsy it is

<sup>65</sup> [SUDEP Action and Cornwall Partnership NHS Foundation Trust: SUDEP and Seizure Safety Checklist \(Adult\) \(2020\)](#)

possible to reduce premature death. They have developed the 'SUDEP and epilepsy safety checklist' which is now embedded in the NHS Right Care Pathway for Epilepsy.

## Conclusion and recommendations: The night Clive died

**The combined effect of the delay in being able to review all the CCTV footage from the night that Clive died and the discrepancies in the care records leave unanswered questions about how Clive was treated by staff on the last evening of his life. We have also been unable to confirm the time that Clive's seizure(s) commenced, and if there was a missed opportunity to administer rescue medication, Buccal Midazolam.**

Providers should ensure that staff are trained in writing accurate and detailed records and incident reports and should be held to account where these are not of an acceptable standard.

Commissioners (health and social care) should ensure that records are accurate and up to date as part of their regular reviews of care.

**The emergency response by Cedar Vale staff on the night Clive died was limited, confused and chaotic, and may further have reduced his chances of survival. Clive was at higher risk of sudden death due to the complexity of his epilepsy; insufficient safety measures were in place at Cedar Vale to have enabled the staff on duty that night to respond effectively.**

The CQC and health and care (host and placing) commissioners should ensure that care providers supporting people who are at risk of sudden death are able to evidence effective risk assessments and have put appropriate emergency response measures in place, and regularly practice enacting them, to mitigate these.

The Resuscitation Council should review the level of life support training recommended for staff in care settings where they are caring for people with a known risk of sudden death. This should include regular practice of enacting emergency protocols and administering cardiopulmonary resuscitation (CPR).



## 10. Investigations and reviews following Clive's death

**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.**

Research<sup>66</sup> confirms that, from a family perspective, the experience of trying to raise complaints and concerns after a loved one dies is often extremely challenging; they can be met with a set of bureaucratic, defensive, complicated and time-consuming processes. Some families end up dropping their complaints – understandably so – when they are dealing with such grief and trauma. Others fight on, ever more determined to challenge the injustices they and their loved ones have faced. They can end up in an unhelpful and distressing struggle in which the system is seen only to defend itself, in fear of reputational damage and litigation. Clive's family experienced all of this, fighting to get him an inquest, to engage the interest of the CQC and then to achieve commitment to this independent review applying the principles of LeDeR methodology.

Clive's family told us that they wanted two things from this review: first, to get honest answers about how and why Clive died; and second, that actions are put in place to prevent others dying in similar circumstances. The reviews, reports and inquest that took place after Clive died did not deliver this. It is now four years since Clive died – it is not acceptable they have had to wait so long for the answers to their questions or to see actions taken that may prevent the death of another loved family member.

Five investigation/review processes commenced after Clive died. These were:

### 1. Nottinghamshire Police Investigation (January – April 2017)

The police were informed of Clive's death by the East Midlands Ambulance Service (EMAS). Police attendance at unexpected deaths in the community is a standard policing function undertaken within Nottinghamshire, and EMAS are often the agency reporting unexpected deaths. Police attended Cedar Vale on the night Clive died and concluded that it was not a suspicious death. The police subsequently retrieved footage from the CCTV outside Clive's room and provided a log of events for the Coroner's inquest at the request of the Coroner's Office. Nottinghamshire Police have confirmed that if concerns are raised with the police or Coroner, these should be investigated. The family contacted both the police and Coroner's Office in relation to their clear concerns about Clive's care at Cedar Vale, Clive's missing phone and property, and also calls made by Clive to the family in the last 48 hours of his life. No further action was taken by the police. These concerns were left to be addressed by the Coroner's inquest a year later.

### 2. Cedar Vale Level 2 Comprehensive Investigation (April 2017)

A Root Cause Analysis was undertaken by Cedar Vale at the request of the Danshell Group Medical Director. The review looked at how Clive's health and care was managed and the action taken by staff on the night of his death. Overall, the review concluded that the level of physical and epilepsy care was of a high standard and that the incident was not preventable as it was due to the underlying ischemic heart disease. Three recommendations were made in relation to recording of seizures, audit of compliance with Danshell Epilepsy Pathway protocols and the introduction of a matrix document to track appointments and actions for service users with complex needs.

<sup>66</sup> [G. Murphy \(2020\) CQC inspections and regulation of Whorlton Hall: second independent report](#)

### **3. South Staffordshire and Shropshire Healthcare NHS Foundation Trust (now MPFT) Clinical Review – Level 2 Investigation (February – April 2017)**

The Trust commissioned to coordinate and oversee Clive's care as part of the Transforming Care Programme initially commenced a review into his death. However, the death was subsequently upgraded to a serious incident and a duty of candour letter was sent to Clive's parents on 15 February 2017. The review documented the involvement of the Transforming Care Programme and looked narrowly and lightly at a number of documented complaints the family had previously made. It was identified that most of these issues fell outside of the remit of the Trust.

It also identified some 'non-contributory' factors, largely around the recording and documentation of actions taken. A single recommendation was made relating to the need for 'a pathway for Transforming Care' to be established and standards for documentation. This was not actioned by the Trust as their contract for the provision of the Staffordshire Transforming Care Programme came to an end in September 2017.

### **4. Nottinghamshire County Council Adult Safeguarding Review (February – April 2017)**

A safeguarding referral was made on 31 January 2017 by the manager of Cedar Vale, advising of Clive's unexpected death as per standard procedure. A safeguarding review was initiated by Nottinghamshire County Council when it became known that the family had raised concerns with the Coroner's Office in relation to Clive's care at Cedar Vale. The review involved members of the Staffordshire Transforming Care team, South Nottinghamshire CCG, Cedar Vale managers and the Lead CQC Inspector for Cedar Vale.

Nottinghamshire Police were invited, but did not attend. The review was informed by a discussion with the family and two quality visits to Cedar Vale. The review concluded that "there was learning for Cedar Vale and also the CCG in the practice of care; however, the findings of ischemic heart disease in the post-mortem report was significant". Overall, it was noted that Cedar Vale had already put some actions in place and there was agreement that the investigation report would be shared with the Coroner's Office, a further quality assurance audit of Cedar Vale would be undertaken by the CCG and that the case would be taken to the CQC Management Review.

### **5. The Care Quality Commission (CQC) investigation (2018 – January 2020)**

The CQC Inspection Team explored the circumstances leading up to Clive's death, liaising with the local authority, the Coroner and the police following their investigations. They reported that: "The police investigation and the local authority safeguarding review had determined that there was insufficient evidence to pursue a prosecution or further action, against the provider. In summary they found that there had been a delay in obtaining medical attention for Clive and that this was due to individual staff failings."

The CQC concluded that: "Although there were individual failures, these could not be attributed to the provider. Furthermore, the failures that could be attributed to the provider could not be linked to Clive's death." The Inspection Team met with the family in November 2019 to hear further evidence and suggested at this point that the family contact the Parliamentary Health Service Ombudsman. The additional evidence was further considered, but this did not change their decision in relation to the prosecution of the provider.

These processes appear to have been highly influenced by the Pathologist's report that concluded that the cause of death was cardiac-related (see Section 7, part 1: Cause of death and part 2: Epilepsy).

Informed by the expert opinions offered during the course of this review, it is clear that these processes lacked a sufficiently detailed consideration of all the circumstances that led up to Clive's death. Some of these processes drew on each other's findings and further compounded shortcomings. Where learning was identified, the actions to address these issues were not always clear or commensurate and, in some cases, processes awaited the outcome of other investigations before taking action.

Significantly, given that the inquest was not held until over a year after Clive's death, it is evident that the internal review, Serious Incident Requiring Investigation (SIRI) and Safeguarding Review that immediately followed Clive's death largely dismissed the impact of the epileptic seizure due to its exclusion in the Pathologist's initial findings.

Clive shared with his family that he was not happy at Cedar Vale and made allegations that staff were not treating him well. This along with wider concerns around Clive's care led the family to have serious concerns about the quality of care at Cedar Vale. These were raised by the family with the Coroner and police, but were not pursued at that point in time.

The family were unable to assure themselves that Clive and other individuals in the care of Cedar Vale were safe from harm. This led Clive's family to seek answers by accessing and scrutinising the evidence themselves and this subjected them to further trauma. No family should have to listen to the ambulance call centre advising staff on the night Clive died or to examine the CCTV footage as staff administered CPR. Their commitment to seeking justice for Clive and their determination to stimulate changes that will help to protect other cherished family members in the future should be highly commended.

## Conclusions and recommendations: Investigations and reviews following Clive's death

Clive's family requested and pursued a local LeDeR review following his death because they wanted to see learning drawn from the experience of Clive's care and death to improve care and prevent premature death of others. This was not granted by Stafford and Surrounds CCG on the basis that Clive's death occurred 12 weeks before the LeDeR process was formally introduced by the CCG. The family continued to pursue one for several years before this independent review applying the principles of LeDeR methodology was granted by NHSE/I Midlands in view of the exceptional circumstances of this case. The review supports the recommendation of the Oliver McGowan Review<sup>67</sup> that CCGs should effectively 'triage' individual deaths to ensure that the most appropriate governance methodology is used to review them (based on circumstances and complexity).

NHSE/I should take forward the guidelines in the new LeDeR Policy 2021 to ensure that reviewers consider the most appropriate process before commencing a review and that the commensurate level of resource is made available to undertake it.

**Nottinghamshire Police confirmed that if concerns are raised about a death with the police or the Coroner's Office, these should be investigated. The family did contact both the police and Coroner's Office in relation to clear concerns about Clive's care, but no further action was taken.**

The medical examiner system provides independent scrutiny of all non-coronial deaths, wherever they occur and are best placed to guide the Police on what constitutes a suspicious death in a care facility. Medical Examiner Offices should lead work to establish arrangements with the Police and Safeguarding Boards to ensure effective scrutiny of concerns raised about deaths for people with a learning disability in care settings.

**The investigations and reviews following Clive's death failed to consider all the circumstances that led up to his death and may have resulted in missed opportunities to prevent harm to others.**

Where multiple reviews are underway in response to a death, the local integrated care system (ICS) and wider partners should ensure that the coordination and inter-relationship between them is effectively managed to ensure that deaths are looked at comprehensively in an integrated way, to avoid duplication and to minimise the trauma for families.

CCGs and local authorities must ensure that Safeguarding Adult Reviews, Serious Incident Requiring Investigation and other review processes investigating the quality of care or death of individuals, involve families, document their concerns and clearly respond to the issues raised by them.

<sup>67</sup> [F. Ritchie \(2020\) Independent Review into Thomas Oliver McGowan's LeDeR Process: phase two](#)



## 8 Positive practice

**In the course of this review, Clive's family have been keen to highlight positive examples of care and support Clive and the family experienced. Some of these examples powerfully illustrate that it was possible to 'get it right' for Clive with the right support and ethos. These examples can be found weaved across the report and some key examples are brought together in the summary below.**

### Education

In 1980 (aged 11), Clive started mainstream secondary school. The family describe the environment as being very difficult for him in the first 12 months, not because of his ability to participate in lessons, but primarily because Clive could not safely use stairs within the school due to his seizures. Clive became excluded from mainstream education at this point and the local authority offered Clive a placement at Saxon Hill, a specialist school for children with physical disabilities, which the family describe as being 'phenomenal'.

Clive continued to have good days and bad days, but the school is an example of how it was possible to get the support right to meet Clive's needs at a time when seizure levels were considerably high. "It was the philosophy of the school that enabled Clive to thrive", say the family. "They saw his potential and not his epilepsy." They describe Clive having "a rewarding, cherished and continued education, where he thrived and achieved so much with the school's support and love". He was excited for his future.

At the age of 16, with no onward educational provision for Clive to move on to, the school made special arrangements for him to continue with them. Clive's Saxon Hill School report describes him as "an able and engaged individual who organised himself well and helped to organise weekly discos". He strived with the more practical subjects, and it was noted that he was able to "work for long periods unaided and clearly has no difficulty in visualising in his mind the finished product".

### Care provision

Having moved through numerous residential care homes that had struggled to support his needs, in 2002 Clive moved to Suttons Drive, a small residential home offering rehabilitation for people with a learning disability. Clive was settled here for four years, and considered it a permanent home. Clive lived here with five others and four full-time carers. The provision was on church grounds, allowing Clive to go to Sunday Service every week, which he valued as a spiritual person. He attended college, held a work placement at a garden centre and was able to make choices of his own.

The family speak highly of this setting describing it as small and homely where Clive had friends and was happy. He lived the life that he wanted, with days out, garden parties and gatherings that the family would join. Records indicate that Clive's behaviour was more settled while here. The family report that staff had the right skills to manage epilepsy and support Clive's behaviour that provided him with a good quality of life. The family felt engaged and considered themselves 'a part of the team'. Unfortunately, due to a funding dispute, the family report that Clive was moved on in 2006.

## Specialist epilepsy care

In 2010, a new Consultant Epileptologist and Neuropsychiatrist, 'Dr B', took over Clive's epilepsy care and maintained oversight for the remainder of his life. The family speak highly of the quality and continuity of care provided by Dr B. Prior to this, the family struggled with many different clinicians and perspectives with regard to Clive's epilepsy.

Dr B undertook detailed investigations into Clive's epilepsy and worked with the family and care providers to develop longer term plans to manage Clive's epilepsy rationalising the drugs he was on. Clive valued and trusted Dr B and requested to continue under his care when moving out of the area.

## Dedicated Social Worker and Specialist Learning Disability Liaison Nurse

On Clive's return home in 1998, he was allocated a dedicated social worker and Community Learning Disability Nurse. They were able to get to know and understand Clive and played an important role in working with health and care professionals to coordinate his care.

The consistency in support of the Community Learning Disability Nurse was seen as particularly valuable. She sought to track and better understand Clive's epilepsy and played an important role in working with professionals to coordinate Clive's care.

This highlights the importance of a named professional who was able to build a relationship with Clive and his family, but which was lacking for the large part of Clive's life, particularly during his time living out of area.

## Staffordshire Transforming Care Programme Carer Forum

In 2016, a dedicated lead from the Staffordshire Transforming Care Programme took over responsibility for coordinating Clive's care and proactively listened to the concerns the family had. She supported the family by setting up a Family and Carers Forum for Clive's family and two other families. The Forum was seen to be a valued mechanism through which the families were able to support each other and work collaboratively to progress the discharge process.

Individually they had each struggled for many years to be heard and the Forum proved an opportunity to ensure that their voices were heard and that professionals were held accountable for the promises made and delays incurred. The families have continued to support each other and remain in contact today.

# 9 Conclusions and recommendations

## 1. Cause of death

**The post-mortem and Pathologist's report that followed Clive's death failed to consider epilepsy/SUDEP (Sudden Unexpected Death in Epilepsy) as the cause of death.**

Conclusion	Learning	Recommendation
<p>The Pathologist did not follow guidelines on autopsy practice for death in patients with epilepsy, including sudden death, issued by the Royal College of Pathologists which clearly indicated that epilepsy history, seizure history and detailed information on the circumstances of the death were required.</p>	<p>Research shows that SUDEP/epilepsy related deaths are routinely underestimated and wrongly ascribed to other causes. The consequences of this are that valuable information about how deaths happen and how to prevent them is lost. This prompted the Royal College of Pathologists to develop specific guidelines on autopsy practice, the blueprint for pathologists to follow when they investigate the death of someone with epilepsy.</p>	<p>1a) The Royal College of Pathologists (RCP) should review how effectively pathologists are implementing guidelines on autopsy practice for death in patients with epilepsy including sudden death and consider how it can support and reinforce their professional responsibility to implement these guidelines.</p>
<p>Clive's family are one of many families and campaigners who have publicly voiced their concerns about the frequency of 'natural causes' findings in inquests for people with a learning disability. The wider concerns expressed by families and professionals in regard to the number, quality and outcome of the inquests of people with a learning disability, together with the evidence on the under reporting of sudden epilepsy related deaths should be addressed to the Chief Coroner for consideration.</p>	<p>Annual learning from LeDeR<sup>68</sup> has continued to raise concerns about the lower number of inquests conducted into the deaths of people with a learning disability as compared with the general population. There is also evidence to suggest significant under-reporting of epilepsy related deaths that presents a missed opportunity to put in place measures that could greatly reduce sudden death.</p>	<p>1b) There should be a specific communication between the National Director and National Clinical Director for Learning Disability Autism from NHS England and NHS Improvement and the Chief Coroner setting out the concerns from this and other reviews seeking further engagement in the work to prevent future deaths of people with a learning disability.</p>

<sup>68</sup> [University of Bristol LeDeR Annual Reports \(2016-20\)](#)

## 2. Epilepsy

**Clive's epilepsy care overall fell far short of acceptable practice for someone with complex intractable (drug-resistant) epilepsy. At Cedar Vale, his final placement, this placed him at higher risk of sudden death.**

Conclusion	Learning	Recommendation
<p><b>Commissioning of care for people with a learning disability and epilepsy:</b> Clive should not have been placed in services that did not and could not meet his needs with regard to epilepsy care.</p>	<p>The commissioning of care provision for people with a learning disability who also have epilepsy is not sufficiently informed by specialist epilepsy expertise and epilepsy care standards.</p> <p>Those responsible for commissioning care for people with complex needs such as Clive need to be better supported and equipped to commission safe and effective specialist care.</p>	<p>2a) In commissioning care provision (specialist hospital or community) for people with a learning disability and epilepsy, commissioners at a local level (health and social care) should actively assure themselves that care providers are delivering a standard of epilepsy care that is compliant with NICE standards.</p> <p>2b) Commissioning organisations at a local level (health and social care) should ensure commissioners of care provision for people with a learning disability are equipped with or able to access specialist epilepsy expertise to commission safe and effective care for people with a learning disability and epilepsy.</p> <p>2c) Regional NHSE/I Learning Disability and Autism Programmes should undertake a capacity and training needs audit to review the capacity and skills of staff to commission safe care for people with learning disabilities who have complex needs including epilepsy.</p>
<p><b>Epilepsy care coordination and management:</b> Management and oversight of Clive's epilepsy care was often fragmented, and it was not always clear who was responsible overall.</p>	<p>People with a learning disability and epilepsy are more likely to have complex needs and multiple co-morbidities. Often there are many professionals involved in their health and social care, and research shows that this is often fragmented affecting the quality of care received.</p>	<p>2d) Commissioners of care for people with a learning disability at a local level (health and social care) must take action to assure themselves that there is effective coordination between the full network of professionals in primary, secondary and community care supporting an individual necessary to provide holistic person-centred care for people with complex needs with a clearly identified lead.</p> <p>2e) Commissioners responsible for epilepsy care at a local level should undertake an audit of the effectiveness of local epilepsy</p>



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services and support for people with a learning disability drawing on the NHS Right Care Epilepsy Toolkit<sup>69</sup> and NICE standards to ensure they are meeting the needs of people with a learning disability and epilepsy, and that they are compliant with NICE standards of care.

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**Care quality and safety:**

The standard of epilepsy care Clive received in specialist hospital and community residential care settings was often poor and his high risk of epilepsy-related death and sudden death was not always effectively recognised and mitigated.

The learning from this review clearly identifies that the management of day-to-day epilepsy care is critical to the safety of people with a learning disability and epilepsy. The standard of epilepsy care provided in specialist hospital and community care settings, in Clive's case, was often poor.

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.

The high risk of epilepsy-related death and sudden death was not systematically and comprehensively understood or mitigated.

2f) Care providers (specialist hospital and community) must ensure that the care they provide for people with a learning disability and epilepsy is compliant with NICE epilepsy care standards and that all staff are trained in full to meet these standards.

2g) Commissioners of care for people with a learning disability and epilepsy must ensure that care and service providers take a risk management approach to epilepsy-related death, as recommended in the NHS Right Care Epilepsy Toolkit. This should specifically include application of a standard risk template for people living with epilepsy that crosses organisational boundaries, such as the SUDEP and Seizure Safety Checklist<sup>70</sup> tool.

**Epilepsy and challenging behaviour:**

The link between Clive's epilepsy and challenging behaviour was overstated and disproportionately impacted on the generally held view that Clive required a hospital setting, depriving him of the opportunity to better manage his behaviours

Care providers can struggle to understand the relationship between epilepsy and behaviour that is deemed to be challenging, which can lead to inadequate management and support, deterioration in physical and mental health,

2h) With a view to providing better guidance for clinicians, carers and care professionals in relation to epilepsy and challenging behaviour linked to epilepsy and its management, the National Institute for Health and Care Excellence (NICE) should consider reviewing current guidelines in relation to:

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<sup>69</sup> [NHS RightCare: Epilepsy Toolkit \(2020\)](#)

<sup>70</sup> [SUDEP Action: SUDEP and Seizure Safety Checklist](#)

and prolonging his detention.

diagnostic overshadowing and poor decision-making.

- epilepsy and special consideration for people with a learning disability
- challenging behaviour and learning disabilities.

### 3. Health inequalities

**Clive experienced health inequalities from a young age that had a negative impact on his quality of life, some of which caused him pain and suffering for prolonged periods of time and placed him at risk.**

Conclusion	Learning	Recommendation
<p><b>Diagnostic overshadowing:</b> Diagnostic overshadowing resulted in missed opportunities to investigate fully serious health conditions for Clive including underlying heart conditions. This, together with the compounding influence of other factors that were present at his time of death, placed Clive at increased risk of sudden death.</p>	<p>Diagnostic overshadowing is when symptoms of physical ill health are mistakenly attributed to either a mental health or behavioural problem or seen as being inherent in the person's learning disabilities. Clive's needs were very much seen through the lens of his epilepsy and/or behaviours deemed to be challenging. This posed risks for Clive, and sometimes prevented health and care professionals from fully investigating complaints and issues raised by him. The review identified particular challenges in understanding and diagnosing pain which increased the risk of health problems being undetected or misdiagnosed. The issue of diagnostic overshadowing is a critical issue that is also picked up more widely in the series of published annual LeDeR reports.</p>	<p>3a) Health Education England and the Academy of Medical Royal Colleges should seek to ensure that clinical training for all medical, nursing and care staff highlights the issues of diagnostic overshadowing in people with a learning disability who may be unable to express themselves in traditional verbal communication.</p> <p>3b) NHS trusts, GP practices and independent care providers (specialist hospital and community) should provide training to raise awareness of the issues of diagnostic overshadowing for people with a learning disability who may be unable to express themselves in traditional verbal communication and equip them to detect early signs of deterioration using tools and approaches for the management of deterioration.</p> <p>3c) Regional NHSE/I teams should work with health and care systems at a local level to ensure there is a clear focus on diagnostic overshadowing across primary, secondary and community care services and monitor progress.</p>

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**Medical 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.

The review identifies problems with accountability and ownership for the management of medical devices can pose a risk to the safety of people with a learning disability.

3d) Care providers must act in line with the guidance that makes it clear that it is their responsibility to maintain and use medical equipment as prescribed.

3e) Commissioners of care provision (specialist hospital and community) must assure themselves in the regular oversight of care, that individuals have access to and are supported to use medical equipment as prescribed.

3f) The Care Quality Commission must ensure that services are compliant with Regulation 15 (that the equipment that is used to deliver care and treatment is clean, suitable for the intended purpose, maintained, stored securely and used properly) and take regulatory action if these standards are not met.

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**Medication review:** In general, it was not clear how the impact of the range of medications prescribed for Clive was consistently monitored and reviewed.

The review learned that regular monitoring and review of the effectiveness of medications prescribed can be poor, particularly where there are many clinicians and health professionals involved in the care of an individual and when individuals are moving frequently.

3g) CCGs should work with general practices, consultants and clinicians involved in prescribing medication to ensure regular reviews are taken to monitor the risks and benefits of the combination of prescribed drugs at regular intervals in line with NICE Guidance and best practice outlined in the STOMP campaign (stopping over medication of people with a learning disability or autism).

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**Access and reasonable adjustments:** The barriers that Clive experienced to accessing healthcare were not always fully understood and reasonable adjustments made by health and care providers. There were occasions where Clive was not supported to access

The review has learnt that understanding and awareness of reasonable adjustments for people with a learning disability can be poor across health and care professionals. Whilst some needs for people with a learning disability might be more commonly understood

3h) Commissioners of care provision (health and social care) must require care providers (specialist hospitals and community) to fulfil their duties under the Equality Act 2010 to make reasonable adjustments and meet their duties under the Mental Capacity Act 2005.

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important health appointments on the basis that he had refused to go, despite advice and support offered by his family to do so – such as audiology appointments to be fitted for hearing aids.

and catered for such as providing information in easy read, it is important that a more comprehensive understanding of the reasonable adjustments that people with a learning disability might need is actively considered through personalised assessments.

3i) Commissioners should actively monitor that reasonable adjustments are being made through the regular review of care for individuals and through contract compliance processes. Providers should be held accountable where this is not met.

3j) Primary, secondary, tertiary and independent care providers (specialist hospital and community) should provide training to raise awareness of reasonable adjustments and ensure staff are equipped to support people with a learning disability, autism or both to access services effectively.

3k) Regional NHSE/I teams should work with health and care systems at a local level to assure that there is a clear focus on awareness and implementation of reasonable adjustments across primary, secondary and community care services and monitor progress.

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**Duty to promote good physical health:** In some cases, care providers failed to promote good physical health for Clive and failed to recognise and manage the associated risks. For example, Clive gained over four stone in weight in the last eight months of his life because of poor diet and a failure to encourage and enable physical exercise. This affected his quality of life and increased his risk of premature death.

People with a learning disability are at increased risk of being overweight or obese compared to the general population. Issues of mental capacity, poor nutrition and opportunity and access to physical exercise further exacerbates this risk. This review has learnt that there can be poor attention to the promotion of good physical healthcare and meaningful engagement for people with a learning disability, particularly in secure specialist hospital settings.

3l) Commissioners (health and social care) should ensure that processes in place to oversee and review care such as Care and Treatment Reviews (CTRs) are actively reviewing the physical healthcare and meaningful engagement of individuals including monitoring weight gain and physical activity.

3m) The CQC should fulfil its regulatory responsibility to ensure that mental health hospital settings and specialist hospitals for people with a learning disability, autism or both provide good physical healthcare, and meaningful

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engagement and activity in line with established clinical standards and best practice.

3n) As the professional medical body at the forefront of setting and raising standards in psychiatry, the Royal College of Psychiatrists should consider how it can raise awareness and help to improve standards of physical healthcare and meaningful engagement of people with learning disability in specialist hospital.

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## 4. Commissioning and oversight

**Commissioning organisations responsible for commissioning and monitoring Clive's care did not always place him in settings that could meet his needs and did not sufficiently monitor the quality of care he received. On some occasions, this placed him at risk of harm.**

Conclusion	Learning	Recommendation
<b>Person-centred care planning:</b> There is limited evidence of any formal person-centred care planning for Clive before the Staffordshire Transforming Care team became involved in 2015/16.	Commissioners and those responsible for care planning were not always equipped to, or had the capacity to, work with Clive and his family to develop a long-term person-centred care plan. Care planning was often reactive, and commissioners did not always fully assess or understand Clive's needs and consider his long-term aspirations. As a result, he often moved frequently and reactively between care settings that failed to meet his needs.	4a) Commissioners (health and social care) should ensure that all staff who are involved in developing community-based packages of support are skilled in person-centred life planning. Where achieving discharge is proving difficult, they should appoint an independent life planner.
<b>Commissioning capacity and capability:</b> Commissioning organisations responsible for commissioning and monitoring Clive's care did not always place him in settings that could meet his	The role of a commissioner for people with a learning disability is complex, necessitating strategic and person-centred capabilities. Developing good, sustainable outcomes for people with a learning disability requires a	4b) NHSEI National Learning Disability & Autism Programme should review existing quality standards for the commissioning of care for people with a learning disability, autism or both and consider whether further

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needs and did not sufficiently monitor the quality of care he received. On some occasions, this placed him at risk of harm.

well-supported, integrated and sufficiently resourced commissioning workforce, with access to external specialist expertise where it is unavailable within their organisations.

quality standards need developing or strengthening.

4c) Commissioning organisations (health and social care) should ensure that local commissioners of care for people with learning disabilities, autism or both have the skills and expertise to commission care for people with complex health needs that is safe effective and personalised to meet individual needs. The new [Level 5 accredited qualification: commissioning for wellbeing with a learning disability and autism focus](#) can support with this and should be prioritised by health and care systems for commissioner development.

4d) NHSE/I National Learning Disability & Autism Programme should review the uptake of the [Level 5 accredited qualification: commissioning for wellbeing with a learning disability and autism focus](#) and put in place measure to improve uptake where this is required.

4e) Commissioning organisations (health and social care) should ensure skilled supervision and development for commissioners which reflects the complexity of their roles.

4f) Commissioning organisations (health and social care) should review the capacity of teams responsible for the commissioning and coordination of care for people with a learning disability at a local level to ensure they are sufficiently structured, equipped and

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resourced to meet local needs.

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**Procurement:** The procurement process limited the options for Clive, rather than enabling commissioners to build a tailored package of support around him to meet his needs. The opportunities for Clive were restricted by the view that he could only be supported in specific specialised care settings and the limited availability of these services. There needs to be a fundamental shift in the way services are designed and procured to meet the needs of people such as Clive.

Commissioners struggled to identify providers who could provide the specialist care deemed to be needed for Clive's complex epilepsy, as well as the appropriate behavioural support. The option to build a tailored package of care around Clive's needs was not effectively supported. The approach for Clive was largely about finding the 'right placement' to meet his needs, rather than building a tailored sustainable package of support around him. It is vital that procurement approaches support co-produced, flexible and person-centred solutions.

4g) CCGs and local authorities should ensure that commissioners and community learning disability teams are encouraged and supported to develop tailored packages of care around individuals' needs.

4h) CCGs and local authorities should critically review the effectiveness of existing procurement options/frameworks to meet the needs of people with a learning disability and autism in their area.

**Oversight and accountability:** There was ineffective oversight and accountability for the quality of Clive's care overall that failed to address experiences of poor care and led to a prolonged detention of nearly 10 years.

Out of area placements not only disconnect people from their families, but they also fragment continuity of support and make planning and arranging personalised, local solutions more complicated. They also make it more difficult to monitor the quality and effectiveness of services people receive when they are a long way from home. Families cannot just 'pop in' as is more likely in a local setting – which is an important factor in people being safe. This was the case for Clive. Commissioners and those responsible for overseeing Clive's care were often quite removed, did not know him well and engaged infrequently. Those responsible were not always equipped to effectively assess the quality of care,

4i) Health and social care commissioners should ensure that individuals, whether they are in specialist hospital settings, living in residential care, with family or independently, have a named care coordinator who has statutory responsibility for consistently maintaining contact with them and their family.

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particularly in relation to Clive's epilepsy.

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**Preventing hospital admission:**

At the point of Clive's crisis, there should have been alternative options to safely support Clive so that detention may have been avoided.

In order to prevent a person being admitted to hospital, there must be flexible, responsive and skilled capacity in the community. Had there been a better understanding of Clive's behaviours – taking into consideration his experience of trauma – and had his family and care staff been better equipped to support him in the years and months prior to Clive's detention, hospital admission may have been avoided.

At the point of crisis, had there been alternative options to safely support Clive outside of hospital, detention may have been avoided.

4j) CCGs should ensure that there is intensive crisis support available at a local level for people with a learning disability to prevent them from reaching crisis and support them when they do.

4k) CCGs should actively work with carers and care providers to identify and provide support to those at risk of admission at the earliest opportunity possible.

4l) NHSEI National Learning Disability & Autism Programme should oversee and seek assurance that crisis support is available and effective.

**Discharge planning:** There was no concerted discharge planning to move Clive out of hospital until 2015/16 some nine years after his detention. There was no clear evidence that commissioners were driving the hospitals to focus on treating and preparing Clive for community living. This prolonged detention decreased his chances of successful discharge.

Detention could have been ended sooner had there been changes to the nature of the care, support and treatment Clive received whilst in hospital, and if inpatient providers had been challenged to think creatively about how Clive's needs might be met in a community setting.

4m) Commissioners (health and social care) must ensure discharge planning starts before admission, without fail, with a clear timeframe in place. Discharge planning must involve all relevant sectors, who will be involved in providing support in the community working together to think critically about how individuals can be supported to live fulfilling lives in the community.

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## 5. Specialist hospital – care and treatment

**There was a lack of good quality care and treatment for Clive's presenting needs, including NICE-compliant approaches to behaviour analysis and intervention, in the specialist hospitals he was detained. For the most part, responsible clinicians overseeing Clive's inpatient care did not see life outside of hospital as an option for Clive and failed to pursue a timely discharge for him. Alongside the impact of institutionalisation, this moved him further away from living the life he wanted and resulted in an unnecessarily prolonged detention in hospital of nearly 10 years.**



## Conclusion

The findings of this review echo issues raised in the CQC report 'Out of Sight, Who Cares' (2020)<sup>71</sup> in relation to care provided in specialist hospital settings and emphasises the critical need for assurance at all levels so that people with a learning disability who are admitted to assessment and treatment units and other specialist hospitals, receive high-quality, specialist care for short periods, that is focused on discharge.

## Learning

The care and treatment Clive received whilst in specialist hospitals failed to effectively address his needs and prepare him for life outside of hospital. Specialist hospitals failed to deliver a full functional analysis of Clive's behaviour, linking behaviour largely to his epilepsy.

There was an unchallenged view that Clive's needs could not be met outside of a hospital environment, which was not sufficiently questioned or scrutinised by inpatient providers or health and social care commissioners for the vast majority of time he spent in hospital.

The formal renewal process of Clive's detention was not fully understood by the family. They were not always involved in the process and on occasions decisions were taken without assessing Clive's capacity to consent. The processes lacked independent scrutiny; the hearings were informed by social circumstance reports which were not sufficiently robust, authored by different social workers who knew very little about Clive. Having rarely met him, they relied heavily on previous reports and historical records and did not always seek Clive's views.

## Recommendation

Commissioners of specialist hospital provision for people with a learning disability must ensure that:

5a) Before admission to hospital, people have assessments through community teams so that their needs are understood and they have clear and measurable objectives set for their admission to hospital and receive care in an appropriate environment.

5b) On admission to specialist hospitals, further assessments take place, including for autism, sensory, mental health, physical health, trauma, learning disability and any other relevant assessments. This is to ensure that the objectives and care plans are meeting people's needs. There must be a contract in place stating the timeframe for these assessments to take place.

5c) All specialist inpatient units provide a therapeutic environment to enable the delivery of trauma-informed and person-centred care in line with existing evidence-based models. In particular, autistic people must be cared for in small, person-centred units with the right sensory environment, as recommended by the National Institute for Health and Care Excellence (NICE).

5d) Discharge planning must start before admission, without fail, with a clear timeframe in place. Discharge

<sup>71</sup> [Care Quality Commission: Out of sight – who cares? \(2020\)](#)

planning must involve all relevant sectors, who will be involved in providing support in the community.

5e) There must be a named budget holder for the person’s care. Where a new placement is required to enable discharge, the named budget holder, which is likely to be a CCG or local authority, must be responsible for commissioning the identified requirements within an agreed timeframe.

5f) There must be a named community health team lead and a named community social work team lead in addition to the inpatient team and any commissioning professionals for people with complex needs and their families.

5g) There should be a check that families and advocates have full information regarding detention status and their rights and options under the relevant legal framework to enable them to adequately and effectively advocate for individuals – subject to detention under the Mental Health Act.

## 6. The voice of Clive and his family

**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.**

Conclusion	Learning	Recommendation
Clive and his family should have been at the heart of the planning and delivery of his support, but their voices were often not valued or respected. Commissioners and providers	The family’s understanding and expertise in relation to Clive’s needs was not consistently embraced to inform his care. When things went wrong, the family	6a) CCGs should ensure that there is a system in place, which ensures that the views of families are incorporated and reviewed at every level of assurance.

should be required to involve families and carers in care planning, oversight and review.

struggled to have their concerns and complaints heard.

6b) CCGs should ensure that family and carer forums are available so that families can support each other in addressing their concerns with assurance that they will be listened and responded to.

6c) CCGs should ensure access to good quality advocacy, which is an essential safeguard for people, especially people who are non-verbal or extremely mentally unwell, and may be unable to speak up for themselves.

6d) NHSE/I should receive assurance from CCGs that providers of all commissioned services have robust family and patient involvement.

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## 7. Safeguarding

**Clive was not always kept safe from harm whilst in the care of some care providers. The response to the many complaints and safeguarding alerts raised by the family and professionals were inadequate.**

Conclusion	Learning	Recommendation
The concerns and safeguarding alerts that Clive's family and professionals raised over the course of his journey through community and specialist hospital settings were not adequately responded to. In our view, these were missed opportunities to intervene and had these matters been taken seriously, this may have altered the course of events that followed.	Clive's family often struggled to have their concerns heard, even when these were raised through multiple channels with providers, commissioners and regulatory bodies. Where concerns were picked up through formal complaints or safeguarding processes these were not always effectively and independently reviewed.	7a) Local authorities and CCGs should urgently review and ensure that adult safeguarding processes in place to protect people with a learning disability are robust and in line with national guidelines.

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## 8. Safeguarding – allegations of sexual abuse

The safeguarding response to the alleged sexual abuse Clive experienced over several years failed to protect him from further harm and may also have failed to protect others.

Conclusion	Learning	Recommendation
<p>Clive was not kept safe from harm, and it is probable that he experienced sexual abuse whilst in the care of some providers. The safeguarding and police response to this appears to be wholly inadequate. It is a matter of serious concern that this review has not been able to ascertain what safeguarding and police actions followed these serious incidents. These are serious matters and beyond the scope and expertise of this review.</p>	<p>The review proposes that learning from Clive's experience of alleged sexual abuse and how this was managed is specifically looked at through an independent review.</p>	<p>8a) Staffordshire County Council and Cheshire East Council should jointly commission an independently chaired review of the safeguarding response to historic allegations of sexual abuse in 1993, when Clive was placed with a care provider within the Cheshire County Council geographical boundary.</p> <p>The review should explore the national legal framework and processes that were in place on each of the occasions (1993, 1999, 2011, 2015) when the alleged abuse was disclosed, or concerns were raised by staff or family and the adequacy of the responses. The review should specifically:</p> <ul style="list-style-type: none"><li>• Assess the adequacy of the investigations into sexual abuse over the years and confirm its outcome and actions taken.</li><li>• Review and take action in relation to the potential risk to others who came into contact with the suspected perpetrator at the care setting or elsewhere.</li><li>• Identify where opportunities for learning exist.</li></ul>



## 9. The night Clive died

**The emergency response by Cedar Vale staff on the night Clive died was limited, confused and chaotic and may further have reduced his chances of survival.**

Conclusion	Learning	Recommendation
<p>The combined effect of the delay in being able to review all the CCTV footage from the night that Clive died and the discrepancies in the care records leave unanswered questions about how Clive was treated by staff on the last evening of his life. We have also been unable to confirm the time that Clive's seizure(s) commenced and if there was a missed opportunity to administer rescue medication, Buccal Midazolam.</p>	<p>The review identifies issues of poor record keeping. The review highlights the importance of accurate record keeping to ensure effective care and safety of individuals and the need for greater assurance in relation to record keeping.</p>	<p>9a) Providers should ensure that staff are trained in writing accurate and detailed records and incident reports and should be held to account where these are not of an acceptable standard.</p> <p>Commissioners (health and social care) should ensure that records are accurate and up to date as part of their regular reviews of care.</p>
<p>The emergency response by Cedar Vale staff on the night Clive died was limited, confused and chaotic and may further have reduced his chances of survival. Clive was at higher risk of sudden death due to the complexity of his epilepsy; insufficient safety measures were in place at Cedar Vale to have enabled the staff on duty that night to respond effectively.</p>	<p>Care staff on duty the night Clive died had received basic first aid training and some staff had completed this via an online module. Even if there had been a qualified nurse on site, as we know there was, unless staff have the opportunity to practice using these skills, they will have difficulty implementing them.</p>	<p>9b) The CQC and health and care (host and placing) commissioners should ensure that care providers supporting people who are at risk of sudden death are able to evidence effective risk assessments and have put appropriate emergency response measures in place, and regularly practice enacting them, to mitigate these.</p> <p>9c) The Resuscitation Council should review the level of life support training recommended for staff in care settings where they are caring for people with a known risk of sudden death. This should include regular practice of enacting emergency protocols and administering cardiopulmonary resuscitation (CPR).</p>

## 10. Investigations and reviews following Clive’s death

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.

Conclusion	Learning	Recommendation
<p>The review supports the recommendation of the Oliver McGowan Review<sup>72</sup> that CCGs should effectively ‘triage’ individual deaths to ensure that the most appropriate governance methodology is used to review them (based on circumstances and complexity).</p>	<p>The experience of conducting this review highlights principally the importance of working openly and transparently with families. It also reinforces the need to ensure appropriate levels of resource and expertise commensurate to the circumstances of cases.</p>	<p>10a) NHSE/I should take forward the guidelines in the new LeDeR Policy 2021 to ensure that reviewers consider the most appropriate process before commencing a review and that the commensurate level of resource is made available to undertake it.</p>
<p>Nottinghamshire Police confirmed that if concerns are raised about a death with the police or the Coroner’s Office, these should be investigated. The family did contact both the police and Coroner’s Office in relation to clear concerns about Clive’s care, but no further action was taken.</p>	<p>The police rely on duty officers attending a death in a care setting to identify if there are suspicious circumstances. The review has identified the challenges that the police face in determining whether a case is suspicious and the critical importance of drawing on wider intelligence including the views of families and carers.</p>	<p>10b) The medical examiner system provides independent scrutiny of all non-coronial deaths, wherever they occur and are best placed to guide the Police on what constitutes a suspicious death in a care facility. Medical Examiner Offices should lead work to establish arrangements with the Police and Safeguarding Boards to ensure effective scrutiny of concerns raised about deaths for people with a learning disability in care settings.</p>
<p>The investigations and reviews that took place after Clive’s death failed to consider all the circumstances that led up to his death and may have resulted in missed opportunities to prevent harm to others.</p>	<p>Some of the investigations that followed Clive’s death lacked sufficient depth and detail. Some of the processes drew on each other’s findings compounding shortcomings of those investigations. Where learning was identified, the actions to address these issues were not always clear or</p>	<p>10c) Where multiple reviews are underway in response to a death, the local integrated care system and wider partners should ensure that the coordination and inter-relationship between them is effectively managed to ensure that deaths are looked at comprehensively in an integrated way, to avoid</p>

<sup>72</sup> [F. Ritchie \(2020\) Independent Review into Thomas Oliver McGowan’s LeDeR Process: phase two](#)

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commensurate to the issues raised.

Clive's family were not involved in some of the investigations and were not always clear about the outcomes of them. Family members are a critical source of information for investigations into deaths and it is important that their views and concerns are taken seriously. It is also important that they understand what action is taken from any investigations that take place.

duplication and to minimise the trauma for families.

10d) CCGs and local authorities must ensure that Safeguarding Adult Reviews, Serious Incidents Requiring Investigation and other review processes investigating the quality of care or death of individuals, involve families, document their concerns and clearly respond to the issues raised by them.

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