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Independent review into the death of Clive Treacey

December 2021

What this document is about

Clive Treacey had signs of a learning disability from an early age. He also had **epilepsy**, but his **seizures** (fits) were difficult to control with medication.

Clive died on 31 January 2017, at the age of 47. He had a seizure and a **cardiac arrest** (heart attack), but he did not get better.

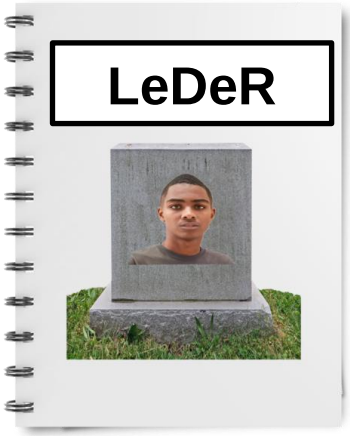
After Clive died, there were **investigations** and an **inquest**. It was important to understand more about Clive's care and what happened just before he died.

But Clive's family still had lots of questions:

- Why did he die?
- Why did he spend so many years in specialist hospitals?
- Why was he not kept safe from harm?
- Why did he not get to live the life he and his family hoped for?
- What happened just before he died?

In July 2020, NHS England and Improvement Midlands arranged for this **independent review**. As an independent team, we looked at Clive's death in lots of detail.

This document is a summary of what we found. The full report is available at: **www.england.nhs.uk/midlands/publications**



Since 2017, **The Learning Disabilities Mortality Review (LeDeR)** programme has looked at the deaths of every person with a learning disability. **They want to:**

- Make sure people with a learning disability get the best health and care.
- Understand why people with a learning disability often die much younger.

Clive died a few months before the LeDeR programme started. Our review was done in a similar way, but it was different because it was led by an **independent chair**, and we asked experts to help.

About Clive

Clive was stuck in a system that could not and did not meet his needs. He moved between lots of **settings** (residential homes and specialist hospitals) during his life.

The longer he was in this system, the less likely he was of ever finding a place to call home.

Clive's health and wider needs were often not very well understood. He was kept in hospital under the **Mental Health Act** for 10 years. This is a law that helps keep people safe and get them the treatment they need. But it should only be used when it is the only option left.

Clive's family loved him very much and supported him at every step in his journey. They complained if they thought things weren't right, but they weren't always listened to.

This independent review

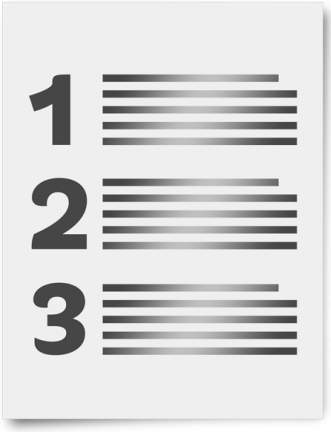
Our review has looked at the causes of Clive's death, and also the quality of the care he received in his lifetime. **We have:**

- Listened to Clive's family.
- Looked closely at his health and care records.
- Heard recordings of the inquest.
- Spoken to people who cared for Clive.
- Asked experts to give their thoughts on the evidence.

Through our review, we wanted to:

- Build a picture of Clive, his needs, and how well they were met.
- List and date all the services Clive received and the places he lived.
- See if anything could have been done differently or if any lessons could be learnt about the care he received.
- Find examples of where Clive had good experiences and his needs were met.
- See if anything could be done differently in the future – to make services better for other people with a learning disability.

Our findings and recommendations



In our review, we have listed **10 findings** and **more than 50 recommendations** (how we think things could be done better).

We have summarised these over the next few pages.

The full report is available at:
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Potentially avoidable

This review finds that Clive's death was **potentially avoidable**.

If some of the care and support that Clive received was done differently, he may have lived for longer.

Findings 1 and 2

1) Specialist doctors called **pathologists** looked into why Clive died. But we found that they did not look into his epilepsy as a reason for his death.

The Royal College of Pathologists
Pathology: the science behind the cure

We recommend that pathologists follow the guidelines from the **Royal College of Pathologists** for when they look at the deaths of people with epilepsy.

2) We found that Clive did not get good enough care for his epilepsy during his life. At his final setting at **Danshell Cedar Vale**, this put him at a higher risk of sudden death.

(Danshell owned Cedar Vale while Clive stayed there, but Cygnet Health Care took over when they bought Danshell in 2018.)

We recommend making sure that **commissioners** (who arrange care) and the **Care Quality Commission** (who check care) know how to make sure that people with a learning disability and epilepsy have good care. Staff need to be better trained to know how to meet the needs of people with a learning disability and epilepsy.

Findings 3 and 4

3) We found Clive did not always have a good quality of life. Sometimes this caused him pain and suffering for a long time. This put him at a higher risk of sudden death.

We recommend that staff are better trained to support people's physical healthcare needs. It is important that they know what **reasonable adjustments** are needed for every individual. These might be small changes that can make things a lot easier.

4) We found that Clive did not always stay in settings that could meet his needs. Commissioners did not always check the quality of his care closely enough. Sometimes this put him at risk of harm.

We recommend that commissioners understand the needs of every individual, and closely check the quality of care. This will help them to get the care they need and a chance to live the life they want.

Finding 5

5) We found that there were lots of times in Clive's life when he did not get the treatment that was best for his needs. This put him at a higher risk of sudden death.

We found that Clive should not have spent so long in hospitals and residential settings. He should not have been kept under the Mental Health Act for so long.

Hardly anyone supported him to be **discharged** (to leave hospital) and get his own home.

We recommend making sure that people do not spend more time in hospital than they need to. The different people involved in their care should work together to plan how they can get home again as soon as possible.

Findings 6 and 7

6) We found that Clive did not have the chance to live the life he wanted. He and his family were not listened to about the best ways to meet Clive's needs.

We recommend making sure that families are listened to. This should happen at every level.

7) We found that Clive was not always kept safe from harm. His family and other professionals reported when they thought things weren't right, but they weren't always listened to.

We recommend making sure that the way we keep people with a learning disability safe is working well. It is important that everyone listens to the person and their family.

Findings 8 and 9

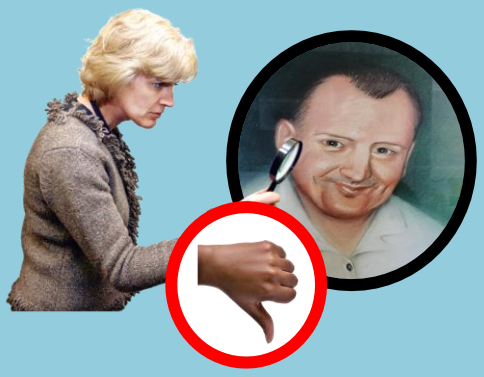
8) Clive and his family claimed he had been sexually abused over several years by someone who was caring for him. We found that he was not kept safe enough from further harm. This means others may also have been at risk of harm.

We recommend that Clive's family's claims of sexual abuse are looked into. It is important to find out what happened to Clive, and how to stop it happening to anyone else.

9) We found that the staff at Cedar Vale could have done more to help Clive on the night he died. If they had done more, he might not have died that night.

We recommend making sure that staff have the training they need when someone needs life-saving support.

Finding 10



10) We found that the reports and checks into why Clive died were not good enough. If they were done differently, they may have helped to keep others safe from harm.

We recommend making sure complaints and deaths are looked into more closely. This includes the way different organisations work together on these investigations.