

Colin Grant discusses SUDEP to help raise awareness for SUDEP Awareness Day 2016



BBC producer Colin Grant has shared his brother Christopher's story to help raise awareness for SUDEP Awareness Day. The awareness day is a worldwide campaign that shines a light on the largest cause of death in people with epilepsy, helping empower those with the condition through increased awareness.

Colin recently published a book, [A smell of burning: the story of epilepsy](#). In his book, Colin documents his brother Christopher's struggle with epilepsy, and how the condition affected him and his family. Christopher was only 39 when he died from SUDEP - Sudden Unexpected Death in Epilepsy, in 2008.

Discussing his brother's epilepsy, Colin shares that his condition remained uncontrolled despite many changes to his medication. Colin says he was aware his brother did not always take his medication as prescribed, as he felt that without it he would at least be 'mentally sharp', opting to run the risk of seizures instead.

In his story published in the Telegraph, Colin says: *"By forgoing medication, Christopher put himself at risk of more seizures, and so at increased risk of injury: towards the end of his life, he was having seizures in the street, banging his head on the pavement and scarring his face. Unbeknownst to us then, people with uncontrolled seizures are also at greater risk of SUDEP - Sudden Unexpected Death in Epilepsy."*

It is vitally important that people with epilepsy take their medication regularly and reliably. This is why this is one of the SUDEP Awareness Day campaign key messages. The campaign also urges people with epilepsy to speak to their doctor before making any changes to their medication in order to reduce their risk.

In his book, Colin also discusses SUDEP, and like many bereaved families who contact SUDEP Action he says:

“I had never heard of SUDEP until I saw it written in the coroner's report confirming my brother's death in 2008”.

This awareness day, Colin has urged everyone with epilepsy and their families to learn about SUDEP saying:

“Find out as much as you can - from informed sources about SUDEP. Talk to medics and organisations such as SUDEP Action, Epilepsy Action and Epilepsy Society about what is known so far about risks and what can be done to minimize risks”

Colin learnt about SUDEP Awareness Day through friends at Epilepsy Society, who SUDEP Action are pleased to welcome as a supporting organisation of SUDEP Awareness Day for the first time this year. Commenting on the significance of the awareness day Colin says:

“Greater knowledge is always welcome as it can help in illuminating risks, and perhaps even stimulate further research”.

You can read excerpts from Colin's story published in the Telegraph -

My brother died from epilepsy. I wish he and I had understood the dangers



When my brother, Christopher, was 18, he woke early one morning, came down to the kitchen and said to me, “Can you smell burning?” Almost immediately afterwards, he toppled over; a strange guttural sound emerged from his lips, he lost consciousness and his limbs jerked uncontrollably.

Christopher had begun having seizures when he was 14. It started with a strange fainting episode in the bathroom - when, after a long time, he did not emerge and failed to answer our urgent enquiries, we broke down the door to find him unconscious on the floor.

Months of tests followed with no diagnosis; eventually, four years later, after I'd witnessed that dramatic attack, it was confirmed that my brother had epilepsy. For a quarter of a century, his life was transformed by the condition, from his first seizure until his final one in 2008.

The smell of burning that Christopher experienced was an 'aura' or hallucination, the kind that some people with epilepsy experience before an attack. If they're lucky it gives them a chance to find a safe place before the seizure ensues.

There was no history of epilepsy in our family. Apart from in very unusual forms of the condition, hereditary causes have not been established. The smell of burning that Christopher experienced was an 'aura' or hallucination, the kind that some people with epilepsy experience before an attack. If they're lucky it gives them a chance to find a safe place before the seizure ensues. As well as olfactory, hallucinations can be gustatory, visual or aural.

After he was diagnosed, Christopher was prescribed sodium valproate, and was told this would lessen the number of seizures, although not necessarily the severity when they occurred. My brother was often irritated by his epilepsy, but he was also amused and intrigued by it, although it put paid to his career as a programmer in the City and led to a life of piecemeal work (which would only last up until a seizure was witnessed by an employer).

Despite all the tweaking of the doses of the sodium valproate, the treatment for Christopher proved ineffective. It was further complicated by the dulling side-effect, so much so that Christopher argued he'd take his chances with the seizures; that way he'd at least be mentally sharp in between. Nagging him continually to relent and take his tablets, the seizures seemed more upsetting for us, his relatives, than for him.

By forgoing medication, Christopher put himself at risk of more seizures, and so at increased risk of injury: towards the end of his life, he was having seizures in the street, banging his head on the pavement and scarring his face.

Unbeknownst to us then, people with uncontrolled seizures are also at greater risk of SUDEP - Sudden Unexpected Death in epilepsy. As the name suggests, there is as yet no understanding of why this occurs. It is rare; only about 600 people in the UK die from it each year out of a population of more than half a million people with epilepsy.

Christopher was 39 when he died following a seizure in 2008. He'd just had a shower and his heart stopped; it seemed he'd had a heart attack but there was no underlying pathology of the heart.

For me, his death was both a surprise and foretold. Christopher had always felt his doctors did not really understand the impact the condition had on him, and dismissed the physical and psychological side-effects of the medication as a necessary evil.

Taken from: [My brother died from epilepsy. I wish he and I had understood the dangers – The Telegraph](#)

Read the book

In his book, Colin shares his brother Christopher's epilepsy story. He talks about how epilepsy has affected people's lives throughout history, and explores how some famous people have lived with the condition. Colin also examines the myths and discusses the evolution of the medical treatment of epilepsy. The book highlights the need for SUDEP to be discussed in order to help people with epilepsy and their families to make more informed choices to help reduce risk.

A Smell of Burning: the Story of Epilepsy by Colin Grant is published by Jonathan Cape. RRP £16.99 hardback, eBook also available for purchase from [Amazon](#)

To learn more about SUDEP visit www.sudepawarenessday.org/what-is-sudep