

'My beautiful girl died in her sleep'

Kerry Cook, 51, is determined to raise awareness in her daughter's honour

Standing in the kitchen, I looked out the window and couldn't help but smile. My nine-year-old daughter Daniella was playing in the back garden with her cousins and they all looked so happy. But soon after, as I dished up dinner, I heard an awful scream. 'Aunt Kerry!' one of my nieces cried. 'It's Daniella!' Panicked, I ran outside and saw my girl was on the ground, shaking and making strange noises. I ran back inside and frantically dialled 999. An ambulance raced to us and took us to our local hospital where Daniella was seen immediately.

Doctors carried out a series of tests, but it took us several weeks to get the results. 'Daniella has epilepsy,' the doctor explained. We

were both shocked, as the diagnosis had come out of nowhere. Shortly after, Daniella and I met with a specialist. He was unsure what caused her epilepsy, but her dad had recently died in a motorbike accident and he thought a combination of stress and hormones were to blame. We looked at our family tree, but could find no history of epilepsy. It was just one of those things.

Over time, the diagnosis turned her life upside down. Sometimes she'd have 20 to 30 seizures a month, with no triggers or

warning signs. Daniella tried various medications to help her manage her epilepsy, and sometimes they'd work, but often they came back with a vengeance. Then her younger sister, Georgia, was also diagnosed with epilepsy when she was 13. As with Daniella, there was seemingly no cause and it took its toll on both of them.

Daniella would come home from school in floods of tears as she'd have seizures and sometimes she'd wet herself. The kids would make fun of her and she'd feel so embarrassed. 'It's not fair mum,' she cried as I tried to comfort her. 'I wish there was something I could do to make it

better,' I said. Daniella would go on dates but it never really came to anything as the boys she was seeing couldn't cope with the seizures. It would leave her heartbroken.

In 2010, when she was 17, Daniella started working.

Determined not to let her epilepsy rule her life, she had various jobs, including one in a snooker hall which she loved. Shortly after she moved into a one-bedroom flat

in Romford. I was hesitant at first, but Daniella wanted her independence and she would be living nearby so I knew I'd still see her a lot.

Then, one day, Daniella came to see me with a massive smile on

her face. 'I've met a lovely bloke at work,' she beamed. 'His name's Reggie and he's so sweet.' The two of them hit it off immediately, and it wasn't long before they were an item. Reggie doted on Daniella, and it was the happiest I'd ever seen her. He soon moved in with her, and was great at helping her manage her epilepsy. Two years later, Daniella announced she was pregnant. I was so excited for her, but as her pregnancy went on, her seizures became worse. She was advised to continue taking her medication, but she developed gestational diabetes which meant it stopped working. At 38 weeks, Daniella had a Caesarean. With Reggie by her side, she had a healthy, beautiful baby boy – who they called Ronnie.

Daniella was a fantastic mum and adored little Ronnie. I hoped

her seizures might calm down or even get better, but unfortunately that wasn't the case. One day, Daniella called me in floods of tears. She'd had a seizure and an electric heater fell on her. Thankfully it wasn't on, but if it was she could've been seriously burnt. We both cried on the phone before I said, 'We need to speak to another specialist to get your seizures under control.'

We got in touch with the hospital, and a few weeks later they sent Daniella a letter. When we read it, one sentence jumped out at us... 'Epilepsy poses a risk for SUDEP,' I read. We'd never heard of SUDEP, so looked it up online. As we scrolled the page, alarm bells went off. SUDEP stood for Sudden

Unexpected Death in Epilepsy – it meant Daniella could die at any moment. Furious, I called the hospital to demand answers. In all the years of both my girls having epilepsy, we'd never been made aware of this condition.

The specialist said there was lots of advice online, but that wasn't good enough. I explained how her seizures were getting worse, and that medication wasn't helping, so she was

given an appointment for two weeks' time. But just a few days later, I received a phone call from Reggie. I asked him to put Daniella on the phone but he said 'I can't, Kerry. She's dead'. I started screaming. My partner put me in his car and drove us to her flat

where the police let us in. I ran into Daniella's room and threw myself on top of her, sobbing and hugging her tight. She'd had a seizure in the night as she slept, and Reggie had found her when he came in from his night shift. She was just a few feet away from Ronnie in his cot. The autopsy revealed SUDEP was the cause of death – her brain had simply switched off. Daniella was wearing her seizure detection device on her wrist at the time, which calls for help when you start fitting, but unfortunately it was broken. If we'd known about SUDEP from her initial diagnosis and how serious it was, we could have kept a closer eye on it. I would have moved in with her to make sure she was never left alone.

My beautiful girl was just 30 and little Ronnie, who is now one, will grow up without his mum. Reggie is absolutely devastated and my daughter, Georgia, 26, is terrified the same thing could happen to her. That's why I've donated Daniella's brain to science, and have a petition calling on the Government and medical profession to be braver and talk to their patients about SUDEP. Understanding how to manage your seizures and having access to the right level of support is so crucial. It could make the difference between life and death. It might be too late for my Daniella, but I want to help save others and I know Daniella would have wanted that, too.

● To sign Kerry's petition, visit change.org/p/sudep-epilepsy



Kerry and her daughter Daniella



Daniella's life was tragically cut short



Reggie, Ronnie, and Daniella



She was a doting mum



With baby Ronnie

'Her seizures were getting worse'

'I want to save others'