A little more – July 2026

I wrote Alan's My Story the year he passed. Writing poems, raising awareness, planting things, were all in remembrance of him. He will always be my first born, my parents' first grandchild, and I will never ever forget him being born – looking up with the biggest blue eyes and smiling. He was the perfect baby, a delight, and my heart would ache if he was not close by.

His brother arrived the following year so there were only 14 months between them.

As soon as he could walk he would go from my parents' kitchen hall to the living room. He had speech therapy and struggled with the word 'animal'. He was so proud when he was finally able to say it. He went away with friends aged 11 and I stood and cried. I always had a fear of losing him.

He was a brilliant golfer but didn't want to go professional. He didn't like pressure. From late teens to early 20s I'd ask him where he was going, and he'd reply 'why, do you want to come?'

He'd come home after I had gone to bed, but I would not sleep until I knew he was in. Many times, he would come to me and lie on the bed, and we'd talk. They were lovely times. I'd ask him if he was OK, and he would always say that he was.

His seizures began in his mid-twenties, I still believe they started from knocks to the head. My argument has always been that if I could have shown him something about SUDEP he'd be here now. Alan would always help a friend and was always there to listen.

My car contains leaflets about SUDEP and if they save just one person it would help me make sense of losing him at 30.

The morning that he died we'd gone to finalise details about our wedding. We arrived home to find a policeman at the door. I just knew it was awful news. Now, there are so many lingering if, buts and maybes. With the correct medication he would have been able to drive again. His cousin picked him up from work because he didn't feel right the week before he died. I see so many things now, but I was the over-concerned mum who was over-reacting so he would say to people, 'don't tell mum'.

I don't know how I've got this far. Mum died when Alan was three and Dad died two years after Alan. Alan's brother Nathan misses him dreadfully, I only really realised how close they were after Alan had died. As my mum used to say, 'you love all your children the same but in different ways'. Nathan has so many of Alan's ways and I can say I'm proud of them both, but there is always the heartache of missing Alan, holding him or hearing the sound of his voice.

Some things remain shocking. Finding out there were so many families who first found out about SUDEP from a post-mortem report.

The wait for Alan's body to be released. The heartbreak when the police blurted out 'they've taken your boy's brain'. No one asked for permission. Alan loved his hair and was always having it cut, nicking my hair products. I still have products with 'mum's' written on, not that it made a difference. I refused to have the funeral without him complete. My baby my son who was born perfect.

Even now I still have questions. I have his ashes with me, and they'll be with me when I go. He hated to be alone. It's the last thing I can do.

Knowing Alan still makes a difference, raising awareness of SUDEP, is a comfort and it's a joy when people say his name. There is hurt when people change the subject.

Thank you from Alan and Nathan's mum. And a special thanks to Nathan, who ensures that for every occasion there are two cards, one blank, as Alan always said it's the thought that counts. Every June 2nd we have a day out together. When I remarried on 10th October 2015 – Nathan's 30th birthday – Alan came with us, his brother proudly holding his ashes.

Many thanks for reading.