Emily (22yrs)

Emily was 22 when she died of SUDEP in May 2012, 4 days after her final exam at University. Her diagnosis of juvenile myoclonic epilepsy at age 14 had never stopped her enjoyment of life and with her exams behind her, she was looking forward to starting out in life, her head full of plans and dreams, excited by the possibilities ahead.

Her sudden death was a cataclysmic event for her family and friends. At the time, I likened it to a huge explosion. Initially, I could not see or hear anything, or feel the ground beneath my feet. The world I thought I knew had gone and I had nothing to hold onto. The year's wait for the inquest with its final verdict made it hard for us to find a way forward, as we coped daily with not-knowing and other people's guesses and assumptions. Then, gradually, over the years, the dust settled and we started to slowly rebuild our lives out of the wreckage.

For me, grief is an experience made easier by sharing, both with professional counsellors and friends. Almost everyone wants to help and make it better, particularly in the early days. Of course, it cannot be made better and amidst the loving support, there were some occasions when someone would unintentionally say something completely inappropriate and occasionally hurtful. But somewhere in my head, I always have the phrase 'they mean well'. Most helpful were those who did not try to make it better but simply came alongside and were with me in whatever place I was in.

It was shortly after her death that her dad contacted SUDEP Action. Her epilepsy nurse had suggested that SUDEP was a likely verdict and he found the charity when looking for information online. Through them, we have found support and friendship, as well as an opportunity to use our experience to help others. Each time we share our loss is a moment of exposing our deepest vulnerability. But we know the importance of sharing stories, and with the support and sensitivity of SUDEP Action, we are enabled to do so and help the charity in raising awareness, supporting families, and preventing future deaths.

During the year after her death, we decided to walk the Pembrokeshire Coast Path in her memory and as a healing for us. We took our time, walking when the weather was nice, in small sections that usually included a café or pub, and weaving the story of our walk with our memories of Emily on a blog. Sometimes we were joined by friends and family and it provided a focus in the early years, walking and remembering together, along the land's edge.

Our lives are not the same and the sense of loss has not lessened. The grief has not disappeared, but it has changed, popping up at expected and unexpected times: sometimes still intensely painful, but occasionally also heightening joy with love and golden memories. I allow it to come and go, and accept myself as I am in each moment. I was a busy advisory teacher at the time of her death, but can no longer work at the same level, and now live more simply on a smaller income, taking each day as it comes. In this slower pace of life, I find I am more in tune with the natural world and the healing it offers, and I have more time for friendships and the things that matter.

Our year has a different pattern now. We experiment with alternative ways to celebrate Christmas and Easter, but 8 years on, are still struggling with these. We spent our 8th Christmas without her with our older daughter's in-laws and had a relaxed and happy time. But other family gatherings are hard as we feel the empty space. Her sister's wedding came 2 years after her death and was an emotional roller coaster, and we simply accepted the mix

of emotions. There is still happiness to be shared in the milestones of others. Many of her friends keep in touch and some have invited us to their weddings, which we have enjoyed, knowing how happy Emily would have been for them. As the years pass, so others' lives move on and away from the anniversaries. We mark her birthday each year with chocolate cake (her favourite), a walk or a visit to somewhere that she loved and a nice meal. We give her age in a donation to a charity which would have meant something to her – my favourite was when we were sitting in the kitchen one year wondering who to donate to when a local child knocked at the door looking for sponsorship for a local wildlife charity event. His eyes widened when we gave him £26. We also plant her age in bulbs, often in forgotten pieces of land for other people to have the joy of discovering. The anniversary of her death creeps up each year, preceded with an uninvited sense of dread. We start asking each other why we feel so low, then remember the date. This is a time of difficult memories and we each mark it in our own ways. Her Dad and sister like to keep busy and distracted, I find comfort in quiet and simple rituals. It is a time for tenderness and extra compassion.

Her grave has become less important as the years pass. We could not get there for the anniversary this year due to COVID-19 and we realised that we no longer felt the need in the same way. It is still a place where I go to sit quietly, my back against the warmth of her stone, where I can allow my feelings to come and go. I love to watch the flowers we have planted and those that have self-seeded as they come up, but I am more likely to go when the weather is good now, particularly on a summer's evening. Our love for her is in our hearts, not in the ground.

So things continue to change as we find new meaning and ways of being in our lives. If I had to pick out a key word for the last few years, I would choose acceptance: A gradual and reluctant acceptance that Emily has gone, and that we and our lives are forever changed as a result; that whilst we carry the sadness, there are times of joy and happiness; and that there are still adventures to be had. She is not here to share them with us, and somehow, most of the time, we have come to accept that and can go forward with Emily always here in our hearts and minds.

Kate (Emily's mother)