

I lost my Mum to SUDEP back in 2007. For the most part, I felt like I had 'come to terms' with her death. Besides, I had an amazing life that I was very grateful for. I was a long-haul flight attendant and I absolutely loved my job, and I had great family and friends around me. I occasionally thought about my Mum and felt a bit sad, but I believe in being positive and these thoughts about my Mum were soon overshadowed by "Yes it's sad that my Mum is no longer here, but I have a great life and I feel very lucky!"

Then COVID-19 and lockdown hit. My airline stopped flying and I was spending all of time inside my little studio flat (I live alone). At first, it was a novelty and I chose to enjoy it - I'm an introvert so I enjoy alone time, and I was enjoying all the benefits of not flying long-haul such as having a normal body clock with no jetlag!

Then I found myself thinking about the past a lot. I had no present (because I was doing the same thing every day and wasn't able to leave the flat) and I had no future (I didn't know if my airline would survive the pandemic and if they didn't, I had no idea where I would work or what kind of job I would have instead), so it seemed like the past was all I could think of. I thought of people who picked on me at high school and I was able to move from being angry with them to feeling compassionate and forgiveness towards them.

But when it came to thinking about my Mum, all I felt was guilt and sadness and I didn't feel physically able to move past this. My Mum died when I was 17 and I was a typical moody teenager at that time - during the time of her death, I feel like I didn't appreciate her. A few memories really stuck out in my head where I felt like I hadn't been that nice to her. Once, she had a seizure in my room in the middle of the night and after the seizure (because she was confused and didn't realise that she wasn't in her own bedroom), she tried to get into my bed with me. I was irritated and sent her to her own room. Looking back, I feel incredible guilt that I didn't go to her room with her that night and make sure she got into her own bed safely. Another time was her 50th birthday (she died when she was 51 so not long before), we went out for a family birthday meal and I was being moody.

During lockdown, I remember having two days where I just cried hysterically over my Mum and I didn't feel able to stop it. I like to think that I'm a logical person and the logical side of me was trying to say that this was all in the past, and it was physically impossible for me to change it, so why am I getting so upset over it? In a way, I'm kind of glad that lockdown brought these emotions to the surfaces, as they were maybe things that I hadn't dealt with or processed in the 13 years since my Mum died. I knew I was feeling so awful that I really needed professional help. I'm grateful that SUDEP Action exists as while there is nothing wrong with speaking to a generic counsellor or bereavement service, there was something that felt good about someone who specifies in SUDEP.



On the day that I was due to have my first call with Tracy, I felt excited and I was proud of myself that I was being proactive and actually doing something to help myself during this difficult time. Tracy was so lovely and friendly and completely put me at ease.

The phone calls are a bit of a blur but I'm naturally quite an open, honest person and I was happy to just say exactly what I was feeling and get it off my chest. Part of me felt a bit silly that I was getting so upset over my Mum when she had died 13 years ago, but I knew that these emotions had been brought on by lockdown (which is such a strange, unprecedented thing in itself) and Tracy assured me that it was okay/normal to be feeling this way. While there is nothing wrong with opening up to friends and family when you're sad, there's something that felt really 'safe' and reassuring about speaking to someone who specialises in SUDEP deaths.

I remember Tracy saying that during our series of phone calls, I may feel worse before I began to feel better, but not to let this put me off. I thought of a metaphor for this - it's like having a piece of glass stuck in a wound. 13 years ago, I left the piece of glass in the wound and put a plaster over it. Now, I was removing the plaster and the piece of glass. It hurt to remove it, but I knew that it was for the best long term. I was removing the piece of glass and cleaning the wound and long-term, this was a lot healthier and better for me. Another way of explaining this, is the saying 'You need to feel it to heal it' - if you want to truly heal from a traumatic experience, you need to feel the emotions around it. Although it is painful, you will be more fully healed going forward.

After my Mum died, I dealt with it the best I could at that moment in time. Having said that, I actually had no idea how to deal with death, as my Mum's death was the first time I'd lost someone close to me. You expect it to be an elderly grandparent and for the death to be expected, but my first time dealing with the death of a loved one was my Mum's very sudden death when I was only 17. Yes epilepsy was ultimately the main factor in my Mum's death (she had a seizure in bed and had heart failure) but another way of looking at it is that my Mum went to bed one night (she was completely fine and healthy) and she never woke up. When I look at it from that perspective, that is an incredibly traumatic thing for anyone to go through.

After Mum's death, I just carried on with life as normal which I'm kind of proud of. I remember I had my final exams at high school a few months after and then went to university as originally planned later that year. I don't think I deliberately avoided dealing with her death, I just did what I thought was the right thing which was to keep living life. Another thing about my Mum's death which I found interesting is that I was always trying to look for the positive, which stopped me acknowledging/dealing with the negative. For example, my Mum's death was very sudden, and she died in her sleep. I choose to see the silver lining in that she didn't have any kind of long drawn-out illness beforehand, and she didn't suffer or was in pain when she died. She slipped away peacefully. Not to mention that losing my Mum made me appreciate the rest of my family a whole lot more than before, and it really taught me to never take anyone for granted. While there's nothing wrong with being positive (it's one of my favourite parts of my personality), I do believe that I had crossed over into 'toxic positivity' and now I realise that it is okay (and necessary) to acknowledge and process sadness.



As I said before, I'm actually glad for lockdown and having these emotions brought to the surface and it forced me to acknowledge and deal with them (this may never have happened if life carried on as 'normal'). One of the biggest reasons I was so upset about my Mum was the fact that I was in the moody teenager phase when she died. I felt like I was abnormal or 'wrong' for going through that. Tracy reassured me that everyone goes through the moody teenager phase and it's completely normal! She also really helped when she explained that for most people, they go through the teenage phase (when they don't like their parents much) and then come out of the other side of it (when they're friends with their parents again). A big part of what I was mourning and upset over was the fact that Mum and I never made it to the other side of my teenage years. But a parent's love is unconditional, and Tracy reassured me that my Mum loved me even when I was being moody towards her.

The phone calls with Tracy really were so helpful and have helped me cope with my Mum's death going forward. I've accepted that my Mum's death is not something that I will ever fully come to terms with - it will always be sad and painful that she died when I was so young. But I do want to keep living life to the fullest alongside of that - I focus on the good times we had and I always remember how lucky I am that she was my Mum. Even though she had epilepsy, she had a degree in Medicine and was a psychiatrist and lived a very full life. I'm very lucky that I'm a physical part of her and she's still a huge inspiration to me even today.

I want to be happy when I think of my Mum. Something I find myself doing things that I know she would have enjoyed, like going for vegetarian food and then a show at the theatre. Part of me feels sad that she's not there to enjoy it with me, but then it's nice that I'm doing something to keep her memory alive.

One of my biggest takeaways from my calls with Tracy is that it's okay to feel sad. Yes I love the fact that I'm such a positive person, but maybe 13 years of always striving to be positive ultimately had a damaging effect. But it's not all bad - I can feel sadness but still see gratitude and positivity as well.

I'm grateful for my Mum, I'm grateful for my life experiences which have shaped me into the person I am today, and I'm grateful to SUDEP Action for helping me get through this difficult time and have a better, healthier mindset around my Mum's death going forward.

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We understand that this article may intensify memories and emotions of your own experiences.

If you need to talk, please do contact our Support team. It is confidential and ongoing support@sudep.org or 01235 77285