Introduction

“If there is a meaning in life at all,
then there must be a meaning in suffering.
Suffering is an ineradicable part of life,
even as fate and death.
Without suffering and death,
human life cannot be complete.”
(Frankl, p. 76)

I started writing about suffering and death soon after Emily, my youngest daughter, was diagnosed with terminal cancer. Emily was only four years old when we learned she had a rare, aggressive, and incurable brain tumour.

On the second night after receiving her diagnosis, huddled into her hospital bed, I started talking to Emily about the gospel story. Emily listened quietly, and then responded, “Mummy, I think if I go to heaven and none of my family is there, I will be lonely”. I was shocked into silence, realising for the first time that even though we hadn't said anything directly to Emily yet, she must already know that she was dying. Maybe she could feel it in her body. I couldn't speak from the lump in my throat and tears in my eyes, so I held her tightly until we fell asleep.

The next morning, I found Emily inconsolably crying on her hospital bed. In just a few short days, she'd gone from being a normal, happy four-year-old at preschool to being confined to a hospital bed – poked, prodded, scanned, examined, and woken up by nurses for observations throughout the night. Robbed of her normal childhood experience, and confronted by her own mortality, Emily had started sobbing deeply and was hugging me tightly on the hospital bed. Cradled in my lap, the cries came from deep inside of her; they were a cry from the soul.

A doctor, on hearing Emily's sobs, came into our room and asked me what her crying was about. I said to him, "I think this is existential pain more than physical pain". The doctor looked at me wide-eyed and said "Oh…" then quickly changed the subject. Following this, he hastily exited and left us alone. I was stunned. My weeping daughter was staring straight at her suffering; I hardly knew what to say to her and this health professional had run away.

This feeling of awkwardness and being unprepared is understandable: suffering and death are often ignored in Western society. Other ages of human history were closer to death and suffering, whereas with our modern approach to life and medicine, the very sick are often moved away from the home, and the death of a child is rare. That too was my experience. Until death came for my child.

Over the seven months of Emily's suffering, and the three months following her passing, I started waking at 5.00 a.m. almost every morning. At this early hour, I started to write down events I was observing. I also read from authors who had suffered greatly in life or who had looked deeply into the subject. Throughout Em's journey, I confided in many close family and friends, particularly my husband. As a family, we also met together for a time of daily 'devotion' which involved reading, reflection, and prayer each evening. This short journal is the outcome of that time.

The journal reflects on my outward and inner experiences during Emily's childhood terminal cancer and death. Like ripples in water, I observed that what Emily endured rolled over many people in different ways. So, this journal is arranged from my perspective first, then observations around my marriage, my other children, our community, and health professionals. Finally, the climax of this journal is my observations of Emily herself, and then a reflection on my initial thoughts on what we have been given through this season.

My reflections come from my roles within my family as a wife, mother, and full-time carer. I also write from my perspective as a Christian and an occupational therapist (OT), within the Australian context. While all the recollections aim to be truthful, I have tried to protect the privacy of those around me. The stories including my husband and two older children have been used with their permission. I collected these short journal entries over ten months much like a mosaic, pulling together the fragments into loose themes. Therefore, the journal entries switch back in time with each new chapter, as they were written and organised thematically, rather than chronologically.

At the centre of this journal is my Emily, so I wanted to introduce her briefly. Throughout her short life, Em remained a delightful enigma, always doing life in her own way. One of her nicknames in the family was 'Captain Random' because we never knew what she would choose to do next. She was constantly engaged in new craft creations, or pretend play. She loved the inflatable wobbly men at car dealerships, and lighthouses that one could walk up on the inside. Most of all, she loved elephants, and especially her favourite toy elephant 'Ellie'.

Emily was an introvert, and she called herself "shy". She had a small inner circle, with whom she was chatty and funny. She was also stubborn and strong in her sense of herself. In preschool she refused to borrow any children's library books from the school library and insisted on reading only encyclopaedias. Yet even though Em was naturally intelligent she was uninterested in people's praise of her. She enjoyed her accomplishments for her own sake.

Emily also had a gentle and affectionate spirit. In the latter months of her disease, she slowly lost many of her functions, including the ability to walk. One day at home I walked in with a tray full of takeaway drinks for us, and I fumbled it and dropped two of the drinks all over the living room floor in front of Em. Instead of laughing at me, Em gently reassured me, "Don't worry Mummy, I find walking really hard too".

That was our Emily, our free-spirited little girl. This is a compilation of the journal entries I wrote during the crisis of slowly losing her to cancer. This book represents my own imperfect response to an overwhelming situation. It is a story, a tribute, a critique, and a lament. Overall, it is a grappling in faith with one of the cruellest events to witness: the suffering and death of a child.

> Her absence is like the sky, spread over everything.
> (Lewis, p. 12)