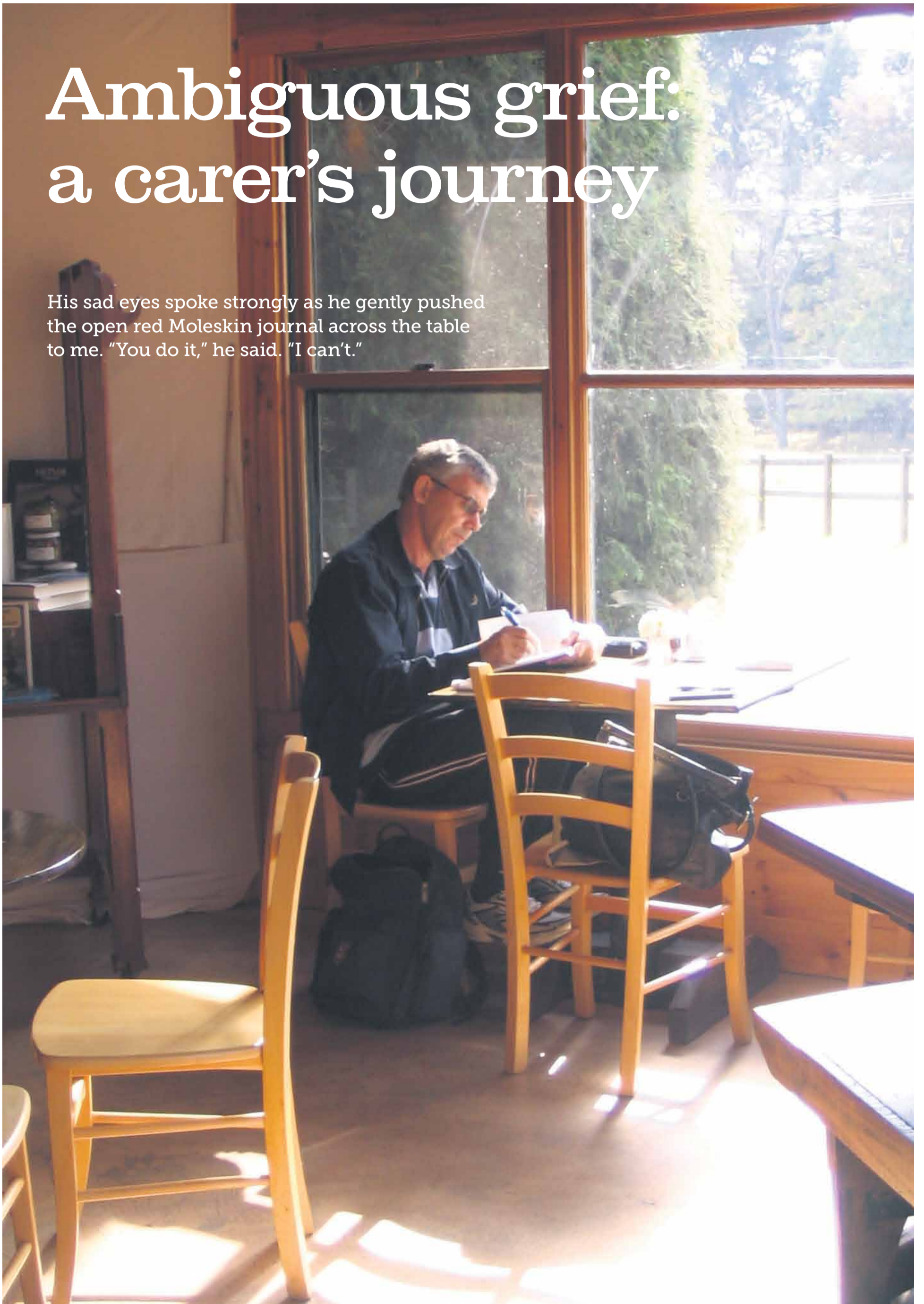


Ambiguous grief: a carer's journey

His sad eyes spoke strongly as he gently pushed the open red Moleskin journal across the table to me. "You do it," he said. "I can't."



Peter had tried for several minutes to write the words of Joshua 1:9 in his journal. He'd written "Be strong and courageous. Do not not be..." but he couldn't get the signals clear in his brain to send the message to his hand to write the next word.

My tears silently pooled on the table top. My beloved Peter would write no more.

There would be no more journal entries. No more songs of worship, no more sermons imploring people to 'keep saying Yes to Jesus', no more poems, no more love letters, no more written insights on life ... and death.

He was still here, but he wasn't.

Ambiguous grief is a painful on-going development for the carer of a terminally ill person. The ambiguity is the physical presence of the one being cared. There are on-going needs the carer yearns to meet yet concurrently the losses continue to close in and contract lives – the patient and the carer.

The losses rarely announce themselves. They sneak up to prematurely and permanently snatch away a piece of life.

Peter didn't realize immediately following the seizure in June 2012 that he would not drive his little Toyota Starlet ever again.

We'd managed six months of Peter not driving following his initial seizure in a hotel bathroom while he was travelling on his own to Benkgulu, Indonesia to speak at a retreat. This seizure meant he could not drive for two years.

At least we were now living in inner-suburbia and Peter could walk to his favourite café while I was at work. Working full-time created some anguish for me. I missed being with him each day but I needed to work to keep our household solvent.

Some days it was painful continuing to remain fully engaged emotionally with Peter on the long journey. As the reality of the coming permanent loss increased, there was a strong temptation to separate emotionally from him to protect my emotional core. The last 18 months of Peter's journey regularly truncated our lives as new limitations silently but clinically imposed new boundaries.

Time after time I felt my heart was breaking as Peter's cancer progressed. I made the calculated decision to stay fully engaged with Peter no matter how difficult it became. Others may choose differently but this was part of my commitment to love and cherish him.

The two and a half years following Pete's 2007 surgery, chemotherapy, radiation treatment and adjustment

to his colostomy bag were amazing. We continued to work together on the Pastoral team at Parkerville Baptist Church.

Peter took his oncologist's advice to heart and ran four or five days a week, even attempting a marathon through the Swan Valley. He was disappointed when his legs would carry him no further and his colostomy bag violently malfunctioned at the 32km mark.

Then the cancer moved to his lungs in early 2010. More chemotherapy and more answered prayer as it stopped growing. The nerves in his toes were damaged by the treatment and running became more difficult, so he walked. The pain in his fingers made it difficult to play guitar. But he was still writing songs for Toddler Jam and family and friends and Jesus.

Next came a brain tumor (May 2011) and the possibility of personality changes and no speech following surgery. We sat side by side on his hospital bed as the winter sun emerged that day, legs dangling over the edge, toes not touching the floor and Peter recorded messages to our two sons on my digital recorder just in case he couldn't talk when he emerged from the anesthetic.

I practiced living in Jesus' presence while the surgeon worked. Would we ever have another conversation together? The implications were like a giant weight pressing into my chest.

Following the successful surgery Peter endured some Whole of Brain Radiation Therapy. Tiredness and nausea crippled him for months until he recovered. His ability to write songs as he used to disappeared. The vibrantly active Peter was slowing down, but fighting hard. We joked that I could almost keep up with him now!

One level of our life contracted further as social activity in the evenings stopped.

We made one last visit to Canada where our little granddaughter was intrigued that Grandpa had no hair except for some soft grey fluff she loved to 'foofle' gently with her pre-school fingers. We all laughed. But the pain in Pete's hips and ribs alerted us something else was happening.

We'd never make that planned trip to Europe together, nor take that road trip down the length of the Mississippi River. The 'together' dreams were vaporizing rapidly now as the cancer moved to Pete's bones.

Sadness overwhelmed me at times. Deep, deep sadness for the things that we planned to do together, the lost opportunities – travel, cross-cultural work, ministering together into our old age, nurturing our family, seeing our grandchildren grow to adulthood.

Physically Peter pushed hard to maintain and celebrate his independence. His last walk to the coffee shop near our home was just three weeks before he died. Some medical people said I should not have let him go alone. But that was his rhythm of life.

The pain of watching the contraction of a life once influential and strategic, falling into a vague netherworld of confusion, pain and isolation was tangible for me.

We took confidence from each other to keep trusting Jesus in these unpredictable times. He walked with us. He understood and could cope with all my fears about the future, the pain of separation and aloneness, the questions about my identity.

But there were many moments of joy too: a magpie eating from Pete's hand in Kings Park; grandchildren putting a white lamb fridge magnet on Pete's bed to keep him company; coffee with friends; laughter; and visits from family living far from Perth.

The ambiguous loss was different for our two sons and other family members. They

came with their families to talk and eat and make music together and pray.

I remember Pete's brother commenting in 2010: "He can still kick a footy better than me. He can't be dying."

We lived some days when denying the reality seemed the natural thing to do so we planned a trip to Sumatra or went out for coffee with the abandon of long term livers!

One day early last summer I heard Pete call out 'shot' as he watched Australia's Captain Michael Clark stroke a cricket ball to the boundary. I smiled at his joy then cried because the day was coming quickly when I would hear his passionate voice no more.

As the tumour grew, Pete's body paid the price. His right leg and arm wouldn't work properly. In the space of three weeks he went from walking alone to using a walking frame, transitioning to a wheelchair and finally being bed ridden... confined, restricted. And he didn't like that.

His speech became confused and the rich conversations we had almost daily for 35 years faded then

disappeared. We honed other communication skills: a smile, a gentle touch. One afternoon a look of fear flashed across his face. He felt like he was out of control and falling over a precipice.

We often prayed together affirming our love for Jesus and asking Him to shape us through this apprehensive adventure.

Through the entire 5.5 years, I was blessed to meet regularly with a friend who graciously listened to me re-playing the last trauma or treatment over and over or asking similar questions month after month, as we drank tea at a cafe in some stunningly beautiful location she has discovered. I owe her and many others much.

Its five months since Peter died. The grief has been gut wrenching and consuming. I believe I've been prepared by my journey through ambiguous grief.

The Advocate writer Jill Birt writes from personal experience about ambiguous grief and loss, reflecting on caring for her husband, Peter, during his cancer journey that ended in November 2012.