CLIVE'S STORY

This is a story about my journey with Clive following his stroke at age 50. I write from the heart with a hope that others may be able to relate to our experience and perhaps bring about change to their own lives.

On September 21, 1991 Clive suffered a massive stroke due to a thrombosis of the left middle cerebral artery. The stroke affected a large area of his brain with swelling of the left hemisphere, pushing the brain stem into the foramen magnum, causing a brain stem compression, which resulted in: *coma;* breathing disturbance; fluctuating temperature – *Increased risk of death as a result.* On day three of his stroke, he experienced a sudden deterioration, a luxury perfusion: the dreaded secondary, perilously threatening any degree of recovery. His many legacies were severe and cruel:

Aphasia/dysphasia: dyspraxia: hemianopia: epilepsy: depression: hemiplegia: perseveration: thalamic pain syndrome: venous incompetence: anosmia/ageusia.

We as a family learnt to live our lives on the edge of a razor blade: moments at a time, looking at nothing beyond. The door on Clive's active life slammed shut on September 21, 1991. We will forever hear echoes of that closed door.

Clive was admitted to Modbury Hospital 21 September, suffered a luxury perfusion three days after the onset of his stroke. On 29 September, he deteriorated; our daughters, Penelope and Sarah, and I stood around his bed praying that he would make it through this terrible, life-threatening phase. Amazingly he did. Although he was transferred to Hampstead Rehabilitation Hospital on 10 October; we were constantly made aware that we had no guarantees for the future.

Through Clive's determination and hard work at therapy, he started to make progress – a new, but different lifestyle started to evolve. Both the girls and I worked hard with Clive to help him achieve his remarkable goals. He was discharged from Hampstead Rehabilitation Hospital as an independent person in a wheel chair on 20 December - he was home for Christmas. He was referred to Hampstead Day Centre in January and discharged in July 1992. A remarkable effort from all concerned; the therapists and Clive worked very hard. Clive worked at the University of Adelaide, Electrical and Engineering Department, he was a problem solver and had put his blue print plan for his future in place.

Although we had many worrying moments with the many legacies Clive experienced, he was so very determined to be the best he could be and worked hard at maintaining a quality life. He learned to walk with his hemiplegia, but the legacy which proved most frustrating was aphasia: he had both receptive and expressive aphasia. He developed a method of getting his message across through 'stick drawings' which helped to relieve the frustrations he experienced when words wouldn't come. But what really stood out, no matter how difficult life became, Clive could still flash his wonderful smile – a smile that spoke a thousand words.

Although we travelled before his stroke with the girls in 1985 and 1987, it was envisaged that we would not travel again after his stroke. Through hard work, Clive's dream came true when we as a family travelled to Singapore and Hong Kong for his 60th birthday; the place he wanted to be on that special day. Although Clive was wheel chair bound for distances, we managed to travel a total of six times between 2001-2011, visiting Singapore, Hong Kong, Bangkok and Cambodia (Siem Reap), each trip spending time in Hong Kong where his daughter Sarah lived. These trips were magic for Clive: he couldn't stop smiling – tapping our arms, weeping and saying 'thank you, thank you!'

As the years progressed, so did Clive, attempting many chores around the house, plus setting up his train table to accommodate his model Ferris train set: his pride and joy. He was a proud owner of a mobility scooter, which further enhanced his quality of life. He also attended a work therapy program set up by his former employer, the University of Adelaide in 1993 which ceased in 2004. Life was travelling along the good lane, if one could described it as that. It has been my philosophy never to become complacent with life – sadly our bubble exploded March 2011 when Clive was diagnosed with terminal cancer – adenocarcinoma of the small intestine and underwent a resection. We made three goals: his 70th birthday June 2011; our planned trip to Hong Kong to spend Christmas as a family that same year: the final goal, Sarah and Stephen's wedding, April 2012. Unfortunately, Clive's cancer returned end of October 2011, we still managed a difficult trip to Hong Kong. The haunting question: 'will Clive be able to keep well enough to give his daughter away at her wedding?' He worked hard at therapy and not only gave his daughter away, but in true style managed to walk with a walking stick instead of a quad for this very special occasion. Everyone was so very proud of this courageous man. The man who's smile spoke a thousand words.

Sadly, Clive was taken into emergency on September 1, transferred to Calvary Hospital North Adelaide where he continued to fight his losing battle; he was eventually transferred into the Mary Potter Hospice for the final phase of his journey. The girls and I lived in with him; they broke away only to feed the cat and let her out in the morning and reverse the procedure for the evening. I did not go home for 21 days. It was a sad time for us all given how hard Clive had worked to get himself the best he could, only to be robbed of the life he had become familiar with. Sadly, Clive died 26 September 2012 – 21 years after his stroke. Penelope and Sarah had lost a wonderful, loving father and I had lost the love of my life – my soul-mate. In remembrance of Clive, we had a leaf engraved which adorns the tree of love, along with many lost, loved relatives of other people who were beautifully cared for by the loving, caring staff of the Mary Potter Hospice.

Journeying with Clive for his 21 years as a stroke person and witnessing first-hand his courage and determination, inspired me to write my book: Echoes of a Closed Door – A life lived following a stroke. The book is my legacy to Clive and in turn his legacy to others who may be travelling along their own difficult journey. The book sends a strong message of HOPE – don't ever give up on hope.

Thank you Clive for placing your precious life in my humble hands. Your soul mate -Carol

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Author: Echoes of a Closed Door – A life lived following a stroke.

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Clive and Carol Fuller

