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AUSTRALIAN APHASIA ASSOCIATION CONFERENCE 2016

CLIVE'S STORY

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In 2002 Clive and I presented at the Australian Aphasia Association conference held in Adelaide; Clive gave a presentation via video on his train table and I as his carer spoke about travelling to Singapore and Hong Kong for his 60th birthday June 2001.

For those of you who are not familiar with Clive’s history: Clive celebrated his 50th birthday on 18 June 1991, three months later on 21 September he suffered his near fatal stroke. Although Clive survived the initial event, including a luxury perfusion and post CVA epilepsy, he was left with both expressive and receptive aphasia, right sided-weakness and a hemianopia. How life can drastically change without warning. The physical legacies from his stroke were visible, but it was the hidden legacies we as a family had difficulty coming to terms with. Not only did we have to get our heads around the terminology; we also had to get our tongues around the pronunciation! Our motto became: *Accept and adjust.*

Before his stroke Clive worked at the University of Adelaide, Electrical & Electronic Engineering Department; he had a problem-solving brain; he was a perfectionist and it was obvious very early in his stroke recovery years that he was not going to allow this ‘aphasia’ to rob him of his personality or the life he worked hard to attain. *‘You can stay in a rut and focus on the negatives, or make the most of what you’ve got and look for the positives’* was his philosophy. Always at the back of our minds was the universal rule: *If you don’t use it, you lose it.*

Early days after Clive experienced his stroke we were struggling to find a way to communicate. Clive had no voice: he couldn’t verbalise. It was during this time that we as a family started to communicate by charades and Clive’s stick drawings which enabled him to try to get his message across. Times were frustrating for us all. I can remember his physician saying, ‘When communicating: treat everyone as if *they* speak a foreign language; use whatever method you can to get *your* message across: charades, stick drawings, use of hand signs etc’.

With the progression of time we engaged the services of Beverley Dodd; who was referred to us as ‘the speech pathologist who welcomed a challenge’. Clive built a good rapport and worked well with Bev, as he had confidence in what she was trying to achieve. Bev set his homework which Clive faithfully did every morning. As his therapy progressed, Clive was encouraged to negotiate his own time frame between appointments, including how much homework he did on a daily basis. But Clive being Clive, he went one step further and negotiated taking Saturdays and Sundays off from speech homework. Most people took the weekends off from work, he reasoned, so why couldn't he? Even though he had suffered a debilitating stroke, he had not lost his ability to negotiate!

In March 1995 Clive attended the first Talk Back Group for people with aphasia, founded by Deborah Hersh. At this group Clive expressed himself through his stick drawings, his way of sharing his intelligence, knowledge and telling his stories. This means of communication continued throughout Clive's post-stroke years. We found it a very successful way to communicate; a few strokes here and there formed a picture and told a story. He later attended the Talkback Group's computer class for a short period of time.

Sometimes Clive couldn't say people's names, he referred to them by numbers. One day when I came home from work he indicated that he had had a visitor – '1,2'. As his story was important to him and to relieve the frustration, I went through my telephone index and called out people's names until I came across the one which to Clive represented '1,2'. The mystery solved to everyone's satisfaction.

Up to the time of Clive's stroke, I was unfamiliar with the role of caring for someone like Clive; the only way I could come to decisions and do him justice was to step into his shoes, ask myself what I would like if the tables were turned; then act on the outcome. I was very conscious to try to get a good balance in life: in my eyes it's not good to have all work and no play. Clive's quality of life reflected on my quality of life and that of our girls.

As Clive had lost the independence he experienced before his stroke, he was now dependent on me his wife/carer/advocate to make his life happen. Clive tried many hobbies: microwave cooking classes; he joined a model train club; tried his hand at restoring his antiques, drawing his old radios and attempted small jobs around the home. We trialled many activities, support groups and programs; including a very successful work therapy program set up by the University.

One of the turning points which broke down the isolation his condition forced upon him, was when we bought a second-hand mobility scooter which we named the 'Red Baron'. Between his therapy activities, Clive was out hooning around on his scooter, meeting friends down at the coffee shop at the local shopping centre, and at times, if I drew the picture and wrote out the name of what I wanted at the supermarket; he ran small errands. I worried if Clive was not at home by the time I returned from work, and would ring around his friends trying to locate his whereabouts. To overcome this and keep in my good books, Clive drew a sign and stuck it to the back door: this most definitely relieved my anxiety. Clive was a very trusting person, but failed to realise his vulnerability: it is the minority of people that can be of risk, I explained.

To add to life's balance and give Clive an incentive to strive to better himself, we travelled overseas to visit our daughter Sarah who lives in Hong Kong. We travelled six times between 2001 – 2011. We visited Hong Kong, Singapore, Bangkok and Siem Reap; each time we spent time with our daughter in Hong Kong. Sometimes we travelled with our daughter Penelope to meet up with Sarah. On each occasion the experience stimulated Clive's speech encouraging him to try to say new words. Clive's physician always encouraged us to travel, saying people with similar disabilities very rarely travelled as did Clive. For Clive and me, travel was definitely a challenge, but the rewards out-weighed the health and financial hardships. These trips were magic – nothing short of a miracle.

It was a sad day for us all when Clive was diagnosed with terminal cancer in March 2011, a sentence he did not deserve given how hard he had worked during his stroke years to get his life back, although a different life from that of his dreams. After Clive's diagnosis he set himself three final goals, the most important of which was to stay as fit and as healthy as his condition would allow - to give his daughter Sarah away at her wedding in April 2012. Sadly, Clive died five months later in September that very same year.

I was Clive's carer from 1991 – 2012, a total of 21 rewarding, inspiring years. Clive's strength to overcome his legacies and live a full life regardless of his condition, inspired me to write our memoirs; a fitting legacy to Clive, who could flash his smile that spoke a thousand words.

Just because you have experienced a stroke and struggle with the legacies; it is not the *end* of life, it is a new chapter *in* life – there is hope in what you are trying to achieve. Never give up.

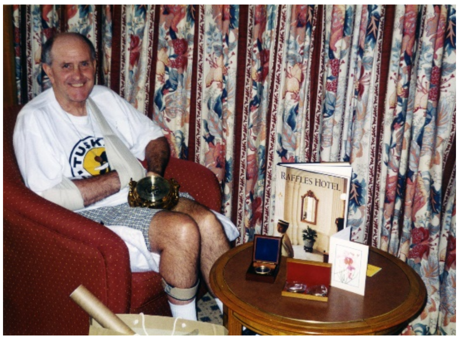
POWERPOINT PRESENTATION

Hong Kong - Victoria Peak

Hong Kong - Lantau Island

Hong Kong - Street Market

Singapore - Street Sculptures



Singapore - 60th Birthday

Bangkok - Bridge over the River Kwai

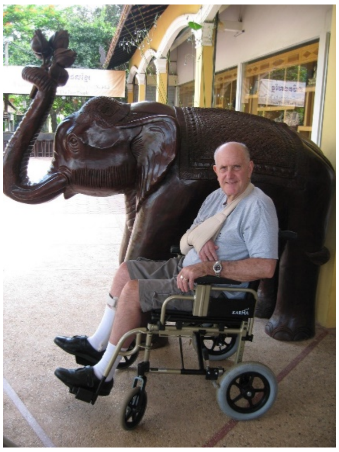
Bangkok – Grand Palace

Bangkok – Chao Praya

Cambodia – Siem Reap

Siem Reap – Ankor Watt

Siem Reap – The Victory Gate



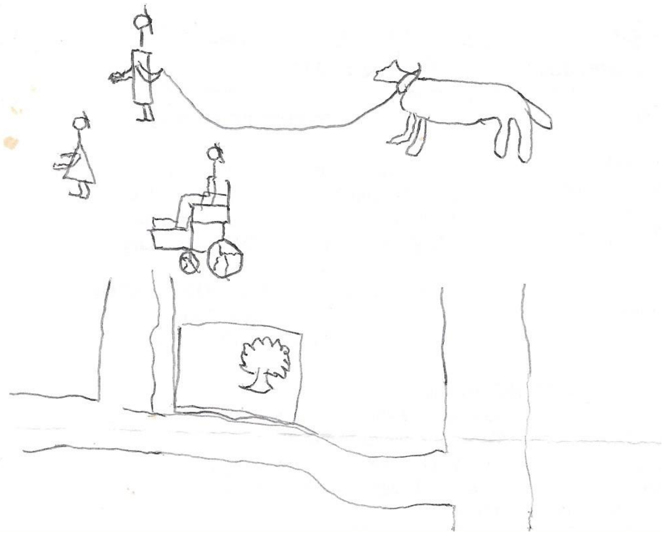
Siem Reap - Shopping


Giving the bride away


The smile that spoke a thousand words

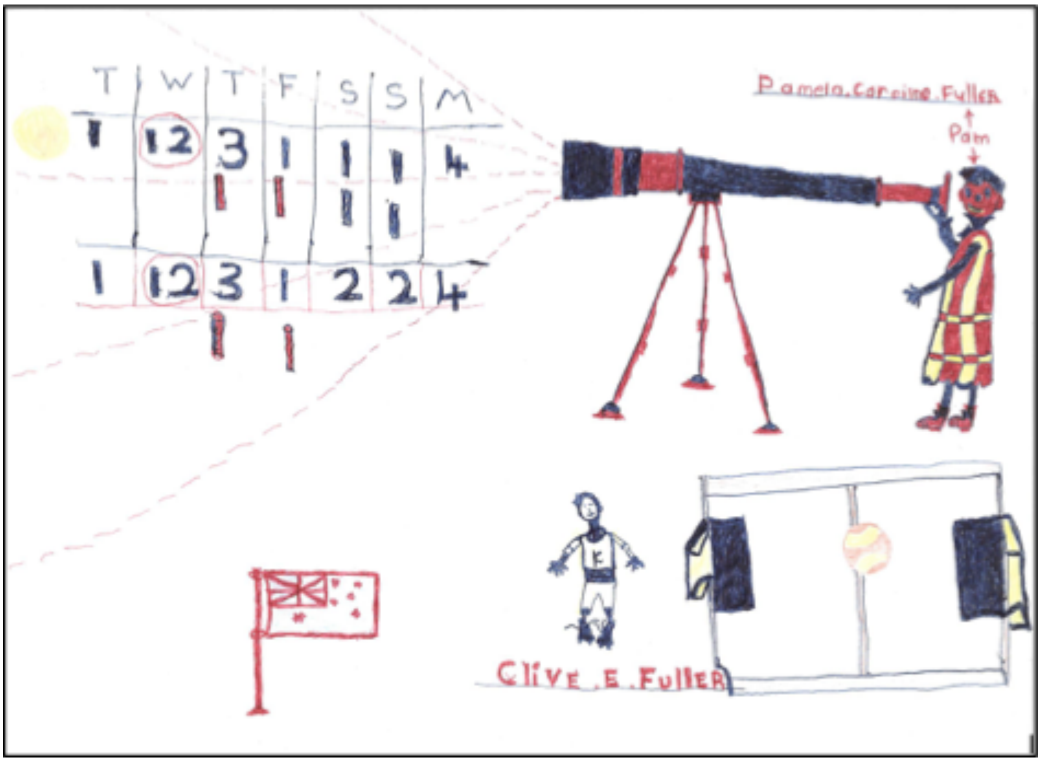
CLIVE'S DRAWINGS

The note Clive stuck on the door

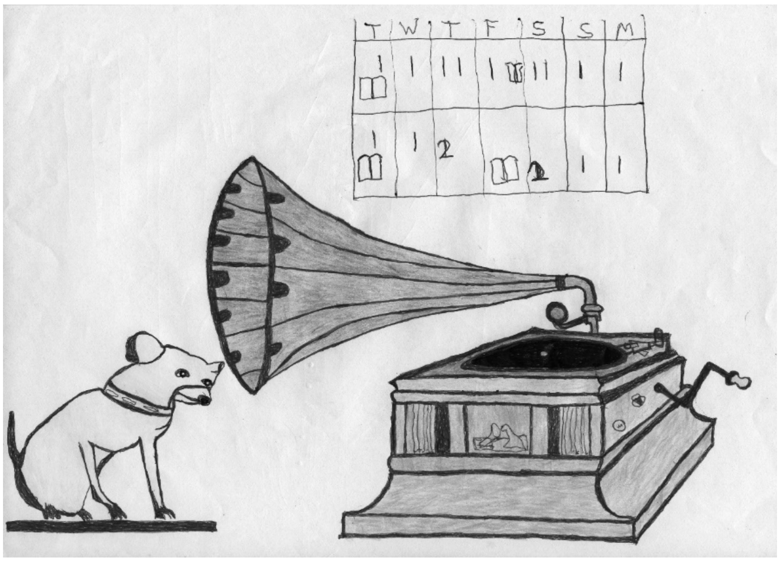


Walking the neighbour's dog – Carol, Penelope and Clive in his wheelchair

Carol playing the piano



Calendar. Pam looking through the telescope. Australian flag. Clive playing soccer.



Clive’s calendar. His Master’s Voice phonograph