



SPREADING THE WORD

30th January 2018

How important is it to keep the focus on issues surrounding strokes? To answer my own question: ***IT IS EXTREMELY IMPORTANT.***

For some of us, when things are going ok, we become complacent: step back and drift along with the flow; ride with the good times. Through experience, I have found that this time is the most vulnerable, when the 'unexpected' can shatter our serene world.

For people reading my article for the first time; my husband Clive suffered his near fatal stroke on 21 September 1991, at the young age of 50; one month before my 48th birthday. Clive and I had two young daughters who were at University at this critical time. This day will remain etched in our minds to the day we die. The door on our previous life slammed shut; the years prior to that date became memories - shadows, the echoes of that slammed door. We as a family, laboriously forged a new life; one of which was so very different to the previous life we had taken for granted and became so accustomed to. It is difficult to describe that change: how we felt, the hurt, the insecurity, the sadness this new life forced upon us; but above all, no one could ever step into Clive's shoes to fully gauge the horrific impact and change Clive endured for the remainder of his life lived as a stroke person. Clive's language was profoundly affected, he suffered both receptive and expressive aphasia. He also suffered a right hemiplegia – he had to learn to become left-handed: his left side became his dominant side. He had so many other legacies as a result of his stroke.

When Clive suffered his stroke, once the initial hospitalisation and rehabilitation phase came to an end, really there was nowhere for him to go. He was fortunate, he was accepted into the Day Centre to reinforce what he had learned during rehabilitation; but Day Centre was short-term; after that – well it was what you could personally find and tap into. As a carer, I knew what we needed for Clive to continue to keep both mentally and physically well, but disappointingly for us as a family, it was nowhere to be found. Clive often indicated: 'what will happen to me now' – 'where to from here?'

I continued to work; our house was not stroke-friendly; major alterations needed to take place to keep Clive confident, functional and safe in his own home. It was at this stage that I planned my own therapy sessions, which I ran from home; I became Clive's case manager – but wearing 'Learner plates'! With the progression of time, his therapy sessions became more tailored and, in my opinion, proficient to his very needs.

In June 1992 (one year after Clive's stroke) a Stroke Forum was arranged by some caring professionals who recognised the lack of services (after care) for people who had suffered a stroke. Clive and I were among the 120 attendees. From this forum, regional stroke groups were formed, of which Clive became a member. The Stroke SA support groups offered not only a place to which to go, but offered companionship for people who had suffered a stroke and their carers. The groups were also a wonderful source of information on services to assist those in need, and to alleviate the fear that they were not alone, and yes, there is a future after a stroke.

In March 1995 the first Talkback group for aphasia, founded by Speech Pathologist Deborah Hersh was formed: Clive became a foundation member of this group. This group offered people like Clive the opportunity to interact with people, who like himself, were struggling with the concept of loss of language; i.e. verbal, written, reading and for some loss of comprehension. Aphasia is very isolating,

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most people cannot comprehend the profoundness of impact, not only for the person who *has* aphasia, but those who *become* involved with that person.

These two groups played an important role in Clive's life: he made many long-lasting friends, and all who had the opportunity to meet Clive were inspired by his braveness, compassion, his wonderful facial expressions and beautiful smile: a smile which spoke a thousand words.

At the beginning of this article I spoke about complacency. In March 2011 Clive was diagnosed with terminal cancer: our bubble of life burst. Sadly, at the age of 71 years, on 26 September 2012, Clive died: he physically stepped out of our lives. I had cared for Clive for 21 years when he no longer could care for himself. He died one month prior to my 69th birthday and five weeks prior to our 50th wedding anniversary. Given the enormous effort of support the girls and I lovingly gave Clive, and his enormous returned effort to become the best he could be over those 21 years; the culmination of events had an enormous impact on the girls and me when Clive died. We felt bruised, battered and broken. We had lost a person who made an integral impact on our lives. ***He was the love of our lives.***

In recognition of Clive's braveness and his journey through life, I wrote and self-published my book: [Echoes of a Closed Door – A Life Lived Following a Stroke](#), which was released September 2016 for Stroke Awareness Week. The book was my legacy to Clive and in turn his legacy to those who are travelling their own difficult journey, and covers the twenty-one years of Clive's stroke: the bad times, the most incredible times and the times 'in between'.

My life with Clive has made me realise that we really don't own our life, it is a gift on loan; but it is what we do with this wonderful gift that counts.

To bring awareness to the impact of strokes, I continue to promote my book and try hard to give back to those organisations which gave us *hope* for a new life; especially during the early phase of Clive's stroke.

On December 7, 2017, I was honoured to be invited to give a shared radio interview to help spread awareness of aphasia, with speech pathologist Lucy Fitzgerald from Talkback Association for Aphasia Inc. The radio segment was presented by Peter Douglas and Elana Jaremyn at Radio Adelaide 101.5FM. [Click here](#) to listen.



Radio Adelaide 101.5FM: Peter Douglas, Elana Jaremyn, Carol Fuller, Lucy Fitzgerald

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For further information about strokes, please contact:

[Talkback Association for Aphasia Inc.](#)

[Stroke SA Inc.](#)

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Author: [Echoes of a Closed Door – A Life Lived Following a Stroke](#)

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