

CONNECTIONS

The magazine of Occupational Therapy Australia, the peak body representing occupational therapy in Australia

August 2017 Vol 14, Issue 4

Print Post Approved PP340742/00147
ISSN 1832-7605

Highlights from the 2017 National Conference

Tributes to OT pioneers
Spotlight on hand therapy
How occupational therapy
helped a stroke survivor
And much more...

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Editorial material including letters to the editor, upcoming events, research material, and important information for inclusion in *Connections* should be sent by email to marketing@otaus.com.au. The editor reserves the right to edit material for space and clarity and to withhold material from publication.

Deadlines for submissions

Edition	Deadline
Oct edition	25 Aug
Dec edition	27 Oct

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CONTENTS

CEO and President's Report	3
----------------------------	---

Key Events	6
------------	---

Policy, Lobbying and Advocacy Update	14
--------------------------------------	----

National CPD Update	18
---------------------	----

FEATURES

Conference Wrap-up	21
--------------------	----

Tributes to notable occupational therapists	26
---	----

The flip-side of the coin	29
---------------------------	----

Spotlight on hand therapy	32
---------------------------	----

Advocacy and Telehealth	34
-------------------------	----

NEWS ACROSS THE COUNTRY

ACT	37
-----	----

NSW	37
-----	----

NT/QLD	38
--------	----

SA	39
----	----

TAS	40
-----	----

VIC	40
-----	----

WA	42
----	----

WFOT Report	43
-------------	----

The flip-side of the coin

Carol Rosemary Fuller 2017

This is a condensed story from Carol Fuller who shares how occupational therapy helped her husband Clive after he suffered from a severe stroke. A heart-warming story from the “flip side of the coin”.

My husband Clive suffered a severe stroke on September 21, 1991 at the young age of 50. He was admitted to hospital in a critical, comatose condition; the stroke was due to a thrombosis of the left middle cerebral artery resulting in loss of blood supply to the majority of his left cerebral hemisphere. At the time of Clive's stroke, the value of thrombolytic therapy (clot dissolution) was still being debated; treatment was supportive. If patients survived the initial event and the complications: oedema, secondary haemorrhage (luxury perfusion), they were left with major neurological deficits. Unfortunately, Clive suffered a luxury perfusion on day three of his stroke, resulting in:

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

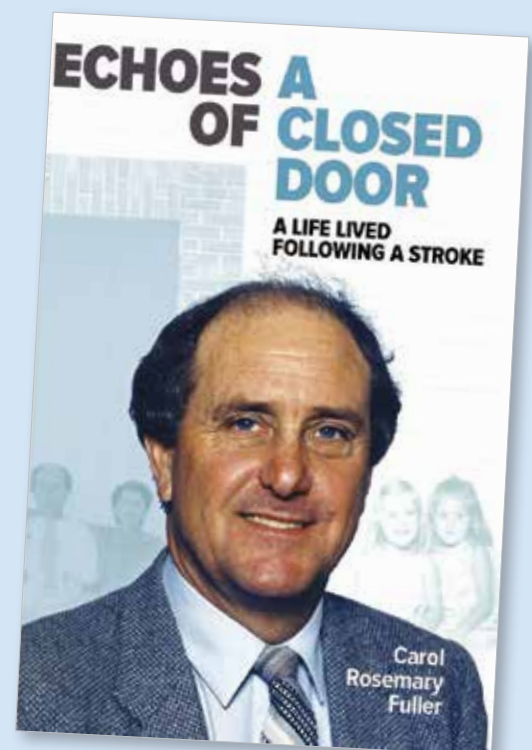
My two girls and I prepared ourselves for the long haul. To understand what Clive was facing, we not only had to educate and familiarise ourselves with the medical terminology relating to Clive's stroke, we also had to get our tongues around the pronunciation. The only way I could give Clive the support he needed, was to step into his shoes; try to feel what he was feeling and continually ask myself: 'What would I want if the tables were turned and it was I who had experienced the stroke?' No one in our families had suffered a stroke.

As it was doubtful that Clive would survive the first night, I lived in with him for the

duration of his hospitalisation. From day two, although still in a coma, I gave him facials, massaged the paralysed side of his body to create awareness of that side; placed his hand over a rolled towel to ensure that it had appropriate support. I exercised his legs; again, focussing on the paralysed side, and supported his foot correctly in an endeavour to prevent his foot from dropping. The girls and I took turns throughout the day to ensure that when Clive regained consciousness, the paralysed side would be 'conditioned' for therapy. We continually spoke to Clive, told him of our love, reinforcing that although he was in a coma, he was still in the land of the living. We played his favourite classical music to try to stimulate his mind – all this in an endeavour to give him hope. The girls and I never, ever ruled out HOPE.

Ten days after his stroke on October 1, Clive regained full consciousness. When the medical team made their rounds, they told him of his severe stroke and the extensive damage it had caused. He lay very still, listening and trying to comprehend what he had been told. He was unable to express his grief, disbelief and despair in any other way than to sob. From day one of his stroke, we as a family had stepped out of our world of normality and stepped into an alien world. We had no guarantees for the present, or a future life together.

As a result of the severity of Clive's stroke and the symptoms associated from his stroke, it was questionable, early days, if he would make any progress. This is



when I embarked on the advocacy side of my now changed life. Clive was assessed and admitted to a rehabilitation hospital on October 10; he started at 'fast stream' level. Clive had a wonderful, problem-solving mind, and I knew if he believed in himself, worked hard with the therapists, and with my personal support he would make positive progress.

The stroke had robbed him of almost a life-time of learning; he had to be retrained

Continued next page

The flip-side of the coin

Continued from previous page

to carry out the most basic of tasks, tasks which we able bodied people take for granted. Clive's occupational therapy programme was drawn up starting at 7am, consisting: toileting, showering, shaving, cleaning his teeth, brushing his hair and dressing; for Clive to be retrained in these tasks was tiring and labour intensive. He then went to the dining room for breakfast, where he had to learn to eat with specialised cutlery. As he had a right hemiplegia, he had lost the use of his dominant right hand: he now had to learn to become left-handed.

We as a family knew that the road to some sort of recovery would be long and hard. I had promised Clive that he wouldn't have to undergo rehabilitation on his own; it wouldn't be all up to him. I, too would be doing my share of the work. Penelope, Sarah and I would become as involved as the staff and Clive would allow us. As I was a working person, Penelope and Sarah often rostered themselves to participate in Clive's activities when I was unable to attend. I was fortunate, most times to work my hours around Clive's routine; I was on hand for all major therapy sessions and meetings.

Clive experienced major set-backs, during his time at the rehabilitation centre; early days he developed a thrombus in his paralysed leg, all therapy ceased until his condition improved. Although the visual signs of the stroke were obvious, it was the hidden disabilities, Clive's 'ugly beasts' which plagued him – chronic fatigue, depression, aphasia/dysphasia, dyspraxia etc; the 'non-visual' associated with his stroke impacted on and hindered Clive's progress. I am of the opinion, all these hidden disabilities need to be factored in when therapy is in progress, they do have a huge impact on the pace of progress and can be erroneously viewed as

someone having plateaued, when actually it is not the case.

Although the days passed quickly; routines remained the same and the rewards of the therapists' and Clive's hard work were now very obvious. There were days when I was asked to participate in Clive's routine of showering, dressing and toileting: this was an 8.30am punctual start at the centre.

Our Burmese cat Temaku, an integral member of our team, played a major role, not only when he visited Clive in the rehabilitation centre, but throughout the years following Clive's stroke: they were inseparable. In the first instance, Temaku was my bargaining tool; he was something from home, something to give Clive the incentive to work hard to ensure that he will be returning to his own home when his time at the rehabilitation centre came to an end. The power of 'pet therapy' is grossly underestimated.

As a result of the therapists and Clive's hard work, he was discharged from the rehabilitation centre on December 20 1991 as an almost independent person in a wheelchair. Our 89-day journey had been long and hard, but we had grown strong together. We as a family were so determined.

In January 1992, Clive attended day care centre to reinforce what he had learnt during his time at the rehabilitation centre. I was under the impression that most gains would be made within eighteen month's post-stroke, which was the time frame I had in mind for his time at the centre. This was a misconception on my part; I soon learned that time at the day centre would be short-term, goalorientated and time-framed. When Clive was discharged from the centre in July that year, I found it difficult to access after care; as a result, we were constantly struggling with our fears and insecurities.

I continued to step into Clive's shoes in an endeavour to make the right choices and to push forward with this new life of ours. I eventually became self-reliant, I developed and ran my own program from home, and when necessary I engaged private therapy to meet Clive's needs.

Clive had a problem-solving mind and was determined to get the most out of his changed life. He soon realised that



Clive's occupational therapy programme was drawn up starting at 7am...

regaining any significant movement or function in his right arm or hand was not going to take place, therefore he focussed on working hard on his new 'dominant' side.

At the time of his stroke, Clive worked at the University of Adelaide, Electrical and Electronic Engineering Department for 27 years (1964-1991). As time passed, it became clear that Clive was grieving for the loss of his working life. He felt isolated, and depressed to the point where he wondered whether the struggle was worthwhile. He couldn't see beyond the moment. In 1993, I approached the University to ask if Clive could attend the University on a regular basis, under the strict supervision of a care person, and perform there some small task. On June 4 1993, a work therapy program was drawn up and signed by relevant parties. The programme came to an end in 2004. T his programme offered so much hope, which was life-changing for Clive. We had

DOOR

A LIFE LIVED FOLLOWING A STROKE

come up against closed doors with other enquiries; a door had now opened and restored our faith in a world that had become very isolating for Clive. A mere 'thank you' seemed inadequate. Clive, due to his aphasia, couldn't express his gratitude other than by repeating 'thank you, thank you'; but the smile on his face spoke a thousand words.

During our journey of 21 years, I was very conscious of providing a balanced programme – all work and no play is not a good balance. We trialled many services/activities – the list is just a brief outline:

- TADSA to alter Clive's tools to enable him to independently carry out small tasks.
- Resumed his hobby of carrying out simple maintenance/repairs to watches and clocks.
- Mowed the lawns and swept the pergola and carried out small gardening tasks.
- Became a member of a model train club. Clive was a proud owner of a model train and train table, which he assembled after his stroke.
- Microwave cooking classes
- A proud owner of a mobility scooter (important for independence and self-esteem).

Clive came to the conclusion early days, that you can self-pity and fall in a rut and let the world pass you by, or you can embrace this new life and move on: Clive focussed on the positive.

In 2001, Clive's wish came true, we as a family arranged to take him back to Singapore and Hong Kong for his 60th birthday. It was a positive incentive for Clive to continue to work hard and move forward with his life, it also made him realise that even though he had suffered a stroke and used a wheel chair for distances, the stroke didn't prevent him from enjoying life and travelling overseas: we travelled overseas a total of six times from 2001-2011.

Clive and I have not ever become complacent nor have taken for granted: life, life's circumstances or the services provided: we appreciated everything the therapists offered. I am of the opinion, it was a combination of their expertise and Clive's willingness to work hard to be the best he could be, which was the makings of a successful outcome. I'm also of the opinion, that all the tasks Clive endeavoured to carry out, plus the encouragement to continue with hobbies worked well as 'disguised' therapy to keep Clive moving forward with his life. Clive got his life back, although a different life from that of his dreams.

Clive and I worked well as a team and respected each other during the 21 years I cared for him when he could no longer care for himself. He was such an inspiring person, no matter how difficult life became during those years, he could always manage to flash his wonderful smile; a smile that spoke a thousand words. He was truly loved by the girls and me. Sadly, Clive was diagnosed with terminal cancer March 2011 and died 26 September 2012 – 21 years after his stroke.

In closing, this brief account of Clive's journey of 21 years outlining his severe disability diagnosis versus determination, hope and love sends a strong message to those in power who make lifechanging decisions on behalf of others:

'Don't judge a book by its cover until you have had time to read the text.'

The book *Echoes of A Closed Door: A Life Lived Following A Stroke* by Carol Fuller is available at the following websites:

www.angusrobertson.com.au
www.amazon.com