



"I see that my life is one of knowing, doing and being. My journey continues on, but now without the knowing and doing of Brian Stanfield.

I must be about my own knowing and doing. For years I counted on, trusted and depended upon Brian's gifted intellect and ability to perform important accomplishments. Now I must know, do and be on my own."

"Just checkin' on ya"

My journey of being a caregiver for a loved one

The palliative caregiver's role is overwhelming and exhausting during the walk with a loved one to Mystery's door. The journey is also filled with excitement and wonder. Jeanette fully embraced her journey with her husband and courageously describes the path for us through her book. It is a great inspiration to read.

*Heidi Holmes, Palliative Care Nurse
Toronto, Canada*

By Jeanette Stanfield



"Just checkin' on ya"

*My journey of being a caregiver
for a loved one*

By Jeanette Stanfield

ACKNOWLEDGEMENTS

I am filled with gratitude to five Australian colleagues who journeyed with Brian and me during this period of our lives and who encouraged me to write this book. Brian and Rhonda Robins were always there with morning or afternoon tea whenever I needed conversation and companionship. Katrin Ogilvy read early rough bits and pieces and gave me courage to keep writing. Margaret Oakley asked the probing questions and listened deeply. Barry Oakley respectfully edited the first draft of my memoir and helped me clarify the structure of my writing.

Marilyn Crocker from Maine USA gave her expertise and loving care to shaping the contextual wrappings for my story and partnered with me to do the final edit. Ben Crocker, her son and a doctor, kindly reviewed and edited the medical terms and procedures I mentioned in this book. John Miesen from Brisbane, shared his publishing wisdom, designed and formatted the cover and book and encouraged me to include photos.

I also want to thank all the people of the healing professions who played their roles in caring for this sacred journey of Brian and continue to care for so many others in South Australia.

DEDICATION

I dedicate this book to Amanda, Brandon, Sarah and Emma in South Australia and to my brothers Russ and Jerry and their families in Illinois and Ontario.

FOREWORD

It is my pleasure to recommend this book. I have journeyed with the Stanfields for many years. I rejoice that Jeanette's experience of caring for her husband will become available for all. Too often the dying process is put into the hands of professionals or is buried with the loved one as too difficult and pain-filled to reflect upon or talk about.

The Prelude section of this memoir introduces two people, separated by the Pacific Ocean, who experienced a similar kind of *unease* about the fractured cultural state of humankind and a *longing* to make a difference. This shared sense of unease and longing eventually brought them together in Australia through their work with a global not-for-profit organisation, The Institute of Cultural Affairs (ICA), and resulted in their focused passion for training local people around the world to work together to build healthy, vibrant human community. Ultimately the product of the Stanfield's research and teaching was a body of writing. These books and curricula have become part of the ICA's tool kit of effective methods for local participation and human empowerment.

This book is devoted to the journey in care that Jeanette and Brian faced in the last chapter of his life. Care is one of the basic ingredients in living profoundly in our world. It doesn't always occur to us that deep care will lead us into expenditure way beyond what we thought we could ever manage. Jeanette was placed in this situation and carefully explored how the agencies of care could help her in her task and how she and Brian could remain in charge of their situation. Her discovery was a spiritual strength to override despair and the eyes to see not dread, but a sense of the last victory in her union with Brian.

Brian was a man of courage and wit. He was teacher to the very end. It was his express wish that he die slowly, probably because he saw that people were not facing death as the last great adventure of their lives. He turned his dying into a teaching experience. What does it mean to have a stroke? We observed as he lost his ability to speak, to eat, to walk and control his natural functions. And do you know what we saw? A pair of eyes whimsically saying: "Get clear what we are talking about here."

As you read about this journey may it also bring courage and strength to you.

Brian Robins, A colleague on the journey.

PREFACE

All sorrows can be borne, if you put them into a story, or tell a story about them.

Isak Dinesen

My intent in writing this memoir is to tell a bit of my story – to share my experience as primary caregiver to Brian Stanfield, my husband of nearly thirty-six years, following a series of strokes that ended his career as brilliant teacher and gifted writer and ushered in the extended process of his dying. During this time we both faced the reality of human fragility from very different perspectives, but both walked the common path toward “saying YES to letting go.” As full-time caregiver to Brian, I learned how to care for myself, in the midst of grief and exhaustion. And after Brian’s life was completed, I learned how to go on without him.

At a time when many of us are called upon to accompany our loved ones in their dying, I hope that my story will help shift our images of the dying process from a status of *taboo*, or at best a *hush-hush conversation* to a respectful dialogue about sacred endings in which we can give thanks for and celebrate “the adventure of dying” as one’s final chapter of authentic living on earth. If this vision is to be realised, close family and friends will need training and support both for sharing this ending time with a loved one and in caring for themselves during this intensely emotional and physically demanding period in their lives.

Jeanette Stanfield
South Australia
2009

PRELUDE

First, I would like to share some highlights about our backgrounds, how Brian and I met, and what our life together was like before his initial stroke began to radically change our world.

Jeanette

My journey began in Wauconda, Illinois, USA a village forty miles north of Chicago. I grew up with my mom and dad and two younger brothers. Wauconda’s claim to fame was Bangs Lake, a holiday spot for city families. Swimming, boating, large rafts and steep slides made it a noisy and fun place on hot summer weekends in the 1940s and ‘50s.

The name of our town always fascinated me. I discovered that it was named after the Native American Chief Wauconda and meant “Spirit Water”. As a child I visualised a tribe camping, fishing and hunting around our lake and wondered what life would have been like for the indigenous people of that land. Many years later when I was a student in a historical geography class at university, I was assigned to write a paper on my home place. I visited our town library and discovered a bit more about tribal life and native peoples’ stories of encountering the deer that gathered by the lake. I remember my breathless moments as a child whenever at twilight I encountered the mysterious presence of a deer along the roadside.

When I was about ten, I received a postcard that depicted a group of children from many cultures who were sitting together talking. I knew I wanted to know more about that world of diverse peoples, and longed to be a part of it. I kept that postcard for many years as a symbol of what I hoped my future might include.

I graduated from university in the early 1960s, a time when civil rights issues were in the forefront of the news. I decided to begin my teaching career in a school run by the Mission Board of the United Methodist Church in the USA. I was assigned to the all black community of Baldwin, Louisiana, located in Louisiana bayou territory , a place as different from my midwest Illinois hometown as any spot in the USA at that time. At age twenty-two I became the teacher of seven and eight year old students at

Sager Brown School and Children's Home and worked there for three years.

For the first time in my life, I experienced myself in the minority. Four teachers at the school were white; all others— faculty, staff and student body — were black. My first year of teaching was absolute agony. I experienced bouts of anger and frustration; many episodes of tears; sudden moments of great determination; and finally, a few breakthroughs in understanding the unique cultural context and needs of my students, which ultimately helped me survive. Few of the teaching methods I had been taught in university seemed to apply to this new cultural context. I had to learn, or invent new approaches. Sylvia Ashton-Warner's insightful book, *Teacher*, was an eye opener. Ashton-Warner had developed effective educational methods to teach Maori children in New Zealand. By looking at what children cared about and inventing ways to teach based on their interests and cultural experience, she was able successfully to engage her students in reading and basic education courses. I began to experiment with her approach. At about the same time, a young black woman who had also taught at Sager Brown for many years became my mentor. I give deep thanks to Phoebe Reynolds for her care for me at that time.

After two years, I decided to return to school for my Masters Degree in Education. I searched extensively for research-based multi-cultural methods appropriate for the teaching of basic skills. At the end of that year I realised there was a dearth of research in this field, and that my years at Sager Brown had probably taught me more about such methods than any university currently could offer. And so, I was still searching.

However, in 1966, I learned about an experimental pre-school operating on the west side of Chicago in an all black neighbourhood. The Ecumenical Institute, through its program division, the Institute of Cultural Affairs (ICA), had initiated a community development project in a sixteen square block neighbourhood on Chicago's west side. In this community, called Fifth City, the ICA staff experimented with an approach called *Imaginal Education* to educate and empower children and adults. I wanted to learn about this, and so became involved first as a program participant, and later as a staff member of the ICA. Since then I have continued to deepen

my understanding of and capacity to apply life-changing methods as an imaginal educator.

Imaginal education as a method of human development focuses on revitalizing images of oneself, one's capacities, and one's context. It is based on the assumption that every human being is valued and has vast, untapped potential. The imaginal educator's tasks are to build confidence, stretch capacity, and motivate human beings to engage actively in life-long learning and to take charge of their own future. This process involves shifting key images of self and the world. As a person's images change, behaviour changes. Imaginal education recovers the dimension of meaning in the learning process as an alternative to only conveying basic knowledge and skills through education.

In 1969, I joined the ICA staff in Sydney, Australia to help set up an imaginal education pre-school for Spanish and Portuguese families living near Paddington, New South Wales. During a series of imaginal education courses the staff was offering, Brian Stanfield, a private school English teacher, enrolled as a participant. He too was searching for more effective educational approaches. Wowed by the power of imaginal teaching methods, he set about using this approach in his classroom immediately. Within six months he decided to become a volunteer with ICA, and soon was taken on as a full-time staff member.

Brian

Born in Sydney on 4 July 1931, Brian and his family moved to Port Macquarie, a small seaside village, when he was five. The sea and the Hastings River became his playground. Boating on the river and bicycling up and down the hills of "Port" provided great thrills and delight. His home was the Royal Hotel in Port Macquarie, where his parents, Mary Grace and Robert, ran what was considered the best dining room and pub in town. His sisters, Jean, age seventeen and twins, Laura and Kathleen, age twenty-five, were more like special aunts to their young brother than siblings. Brian attended the local Catholic schools where the nuns ensured that he learned in a disciplined, rigorous environment, with a curriculum that included Latin, classical literature and music, among other subjects. His love for geography and fascination with the world began

when his mother gave him an atlas and he created scrapbooks about the Second World War.

Brian entered the De La Salle Brothers, a Roman Catholic religious teaching community, and taught English and geography at Kingsgrove school. His religious name was Bruno Canisius. The brothers privately called him Can or Dynamite. Some called him a revolutionary whether he was waking up his colleagues with a water pistol or questioning the direction of the Catholic school system. These were heady times of pre and post Vatican II. The “notorious four Brothers” at Kingsgrove, led by Brian, studied, wrote, created and acted on their own proposals to Vatican II – much of which anticipated the changes eventually made by Vatican II Council in 1962. Lay participation in liturgy was a major initiative. Until this time, students at Kingsgrove attended morning worship but had few avenues for active participation. Brian took on this challenge. First, he insisted that hymn books be made available for all the students. Then, despite minimal conducting experience, he systematically taught the students hymns and the Latin liturgical responses. He edited and published a periodical *Light and Life*, which became a vehicle for the brothers to express their opinions. He also wrote letters to the editor of the *Catholic Weekly*, many of which were published. Eventually his articles in *Light and Life* and his letters, his provocative thinking with his students, and his activities with Catholics for Peace rankled the establishment to the extent that he was asked to desist or leave the community. As one brother later commented, “When Brian decided to do something, he did it to the finish and one had best get out of his way”.

Vin Underwood, one of the “notorious four,” remembers Brian as a voracious reader. “During one holiday period while we were in training Brian and another Brother engaged in a competition of reading a book a day. I don’t remember who won but their competition certainly created a talking point. Brian had a nose, if that is the right term, for sussing out books and material at the cutting edge of areas that were of interest to him.” Exploring bookstores for those books that “jumped out” at him continued to be a favourite activity throughout his life.

Bernie Carney, one of Brian’s students, recollected: “Brian was not only a teacher to us but someone who clearly showed his beliefs and convictions

through his actions. As a De La Salle brother at that time, Brian was a progressive. We all knew that he did and said things that were ahead of their time and that he undoubtedly ‘copped plenty of flack’ for doing so. Nevertheless, Brian always stuck to what he believed and this won him our admiration – an admiration that has lasted for over forty years. Brian had a positive and lasting effect on the lives of hundreds of his students and we are all the better for it so many years later.”

The Stanfield Family

In July 1970, nine months after meeting each other, Brian and I were married. Why did it have to be Brian? Rationally, I thought this was a bit crazy. He was an Australian for one thing. He was Roman Catholic for another and he was shorter than I was! We would look absurd. Somehow I knew with undeniable certainty that he was the one; I wanted to share my life with him. And he must have decided the same thing. Thus began our life together as imaginal educators with the ICA in Australia, the USA, Canada and India.



USA

The next year we left Brian's beloved Australia for a new home in Chicago, where Brian became part of the faculty and later the leadership team of The Global Academy, an intensive 8-week training program in religious and cultural studies offered by the Institute of Cultural Affairs. Gene Marshall, one of the first Academy deans, remembered Brian: "Brian was one of the dearest friends I ever had. He had the sort of integrity, imagination, and dependability that are indeed rare on this earth."

Lis Banks, a Melbourne colleague, and Academy student at the time recalled Brian leading a seminar on Paul Tillich's sermon *You are Accepted*:

"He got a box of Tillich papers, stood on it and eyed everyone and said, 'Yes indeed, I am accepted! Even this one who is 4 feet 11 ½ inches tall is accepted!' A great laugh of delight went through the room. The theologian's point had been made."

India

In 1978 Brian and I travelled to Maliwada, a village in central Maharashtra, India to train villagers in socio-economic development methods and leadership practices through the Human Development Training Institute, a program offered to young people from across Maharashtra State. For us, this was the adventure of a lifetime.

Brian Robins remembers that time:

"Brian and Jeanette were a veritable team by then, and for three weeks at a time they helped train young Indian leaders with high hopes for their nation in what it meant to engage a whole village in determining the way of its future. No antics were too much for Brian if that was what was required to drive home a point. He danced on the table, hid in a cardboard box, and laughed and cried with those 3,000 young people who went through the schools."

Steve Rhea, another colleague from Texas, shares these memories:

"Brian was absolutely one of the finest pedagogues I ever had the pleasure of knowing and working with; a wonderfully creative cook; and superb at injecting humour and life into any situation, especially those that were really stressful and needed that 'otherness'."



Canada

In 1986 we moved to Canada to work with the ICA in Toronto as part of a global research team. To his great delight, Brian was able to initiate and edit *Edges*, a magazine focused on new approaches to human development. Brian researched and shared new ideas and paradigms - exactly what he enjoyed most. For recreation we resumed a childhood love of us both: bicycle riding. The river parks and Lake Ontario trails in and around Toronto provided wonderful settings for long and refreshing rides.

In the 1990s Brian spent most of his days constructing curriculum, researching and editing *Edges* and writing books on ICA's leadership methods and approach to human development. At an age when others were retiring, he was maintaining the pace and productivity of a forty year old. During this period, program participants across the world who had found ICA methods to be effective in their communities and organisations asked for step-by-step guides to allow them to continue to use and share with others what they had been taught. In response to this call, Brian spearheaded the publication of a series of "how-to" books. In 1997 he wrote *The Art of Focused Conversation* with the ICA Canada team. When new members of the board of ICA Canada requested in depth writing on the conceptual framework supporting ICA human development methods, Brian wrote *The Courage to Lead*, which was published in 2000 with a companion journal and study guide. In 2002 he completed *The Workshop Book*.

Ernie Kuechmeister, the principal of a school in Canada and ICA board member wrote the following about Brian:

"I am grateful to have known Brian and to have had the opportunity to 'learn from the master.' It never ceased to amaze me how well he was able to clarify complex issues and put viable solutions within the grasp of groups with very mixed backgrounds and abilities. This was not only knowledge at work; it was the expression of very profound wisdom. From his teaching and writings many more will continue to grow and develop into better world citizens. He has left us a prodigious legacy of good will and insight."

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As electronic communication became available, Brian was able to regularly contact Australian colleagues with whom we had worked in India and the USA. Many of these had returned to their home country. Over the decade of the 1990s Brian and I visited Australia every three or four years, each time spending a few days with friends and colleagues, Brian and Rhonda Robins, and Barry and Margaret Oakley in Adelaide, South Australia. Together with a Melbourne-based colleague, Katrin Ogilvy, we began researching and writing articles on new images for seniors. Although I was still in my fifties, the others were in their sixties, so this area of inquiry was particularly timely and relevant for them. We were able to continue our research via e-mail communication between Australia and Canada.

During this period Brian suddenly stopped smoking the pipe that had been a kind of trademark for thirty years. He said "It isn't fun anymore." He worried about a constant cough that had developed. The high stress lifestyle on which he thrived was beginning to take a toll. When he learned that he had high blood pressure and diabetes, he began to focus on exercise, a lower fat diet, and a more balanced rhythm of work and play. He worked with his doctor and explored homeopathy and acupuncture. He delighted in riding a three wheel electric scooter. We didn't have a car so he used it as his vehicle for local ventures.

In 2001 Brian celebrated his 70th birthday by travelling alone to St. James Bay and the Arctic waters. This solitary journey was a major rite of passage into his eighth decade.

The next year we travelled to Australia for a holiday. After the long trip Brian commented, "I don't think I can keep going back and forth between Canada and Australia much longer. The long distance travel is getting too hard on me. My body hurts and it is hard on my breathing." This galvanised me. I began to sense that something was wrong. I knew I had played a key role in encouraging Brian to leave Australia in 1971. Now it was time to return home with him. By June 2003 we were back in Australia for good.

We moved to Adelaide, South Australia to be near our dear friends the Robins, and Oakleys. We found a house by the sea in Christies Beach,

a place similar to Brian's childhood community. During 2003 and 2004 Brian reconnected with his nephews and niece. He attended a reunion of the class he taught in 1964. He explored his hometown of Port Macquarie, NSW and found one of his childhood mates. He met up with Vin Underwood, his Catholic teaching colleague from the 1960s and we spent some fine days with him and his wife on Kangaroo Island. He took a trip to the sacred Aboriginal site Uluru (Ayers Rock) in the centre of the continent for the first time. His country was welcoming him home.

It was then, in my husband's homeland, that my own identity as an imaginal educator and woman who had always lived out of a sense of possibility was to be most severely tested. Brian experienced the first of a series of severe strokes. For the next two years, beginning in June 2004, I was thrust into a new life assignment – that of guiding and caring for the journey of my husband Brian while he lived the last days of his glorious life and died his glorious death as a man whose gifts and capacities had become extensively diminished.

As the following pages attest, our home and two different hospitals became the new classrooms for learning, and my journal, the notebook for recording new lessons.

Journal entries, reflective writing, correspondence 2004-2008

ENCOUNTERING THE UNKNOWN

June 2004

Brian is weak and sleeping most of the time. He can't walk very well. Saliva flows from his mouth. He is coughing and vomiting. His vision is blurred.

I went with him to the doctor. Blood tests revealed that his sodium level is very low. The irony of this is that for many years since he was diagnosed with high blood pressure, I have been worried about the amount of salt Brian puts on his food. He even buys salt and pepper shakers for his colleagues so he can use them when he visits! I have continued to reduce the amount of salt I use in cooking. Brian ruefully reminds me of this. On top of this, I have also been trying to get him to drink more water, which is helpful, but I worry because this dilutes the salt in his body!

The doctor took Brian off the blood pressure pills which lower sodium and gave him other medications. I now give him salt water, begin regular glucose monitoring, and administer his medications. Within a few days he began to feel much better. I suspect that he hadn't been taking his pills in an accurate and systematic way. His coordination improved, blood sugar remained in normal range, and saliva stopped running excessively. Brian still has trouble keeping food down-particularly in the evening. We rescheduled our main meal to noontime and have a basic vegetable soup in the evening. This seems to help. Sodium is up a bit, but still low.

I noticed that Brian's mental processes seem to have slowed down. He regularly wrote in his journal, but now he hasn't made an entry for thirty days. The computer, which had been his best friend, has become an enemy. Every time he tries to use once familiar computer programs he finds he has forgotten how to use them. When he attempts to type in a thought, he struggles to remember the right word. He yells, "Jeanette, Jeanette come here this moment! Help!!" I have relocated my workstation to be near the computer when he is working on it so that I can be there to respond to his calls quickly. Otherwise, he speaks minimally.

I have begun to keep notes on symptoms and questions to raise with the doctor and I share these with Brian before we go for his appointments. He adds his concerns and questions. I respect our doctor but he has such a short history with Brian that he doesn't understand the changes close colleagues and I see in Brian.

Brian seems to flip-flop between a state of frustration with his inability to perform routine tasks and sudden bursts of energy in a recovered state of competence. (I later learn such fluctuating behaviour is often manifest in stroke victims.)

His coordination and decision-making have become unpredictable. He has always enjoyed fast bike rides but he has never been reckless. Now, however, this play becomes more dangerous. Recently a train conductor and I watched in horror when Brian rode his three-wheel electric scooter so close to the edge of the train station platform that he almost fell a metre down onto the tracks. Upon returning alone from a trip to the mall, he reported to me that he was millimetres from taking the



scooter down the escalator rather than on the moving walkway! After seeing Brian ride alone on his scooter, a friend Trish warned, "Brian doesn't appear totally safe whizzing across the lights at the corner of Beach Road and Roy Terrace. He certainly looks very focused and determined however."

We travelled with the Robins and Oakleys to Morialta in the Adelaide Hills and Brian wrote about two experiences there. "I put the electric kettle on the lighted gas burner! Yesterday I fell again, surrounded by colleagues. I slid on my back towards the rushing creek and a 20-foot drop. Barry Oakley pushed me back from the front; Brian Robins pulled me from the back. Finally I was able to get on my knees and pull myself up and away. A bushranger (park ranger) came along and took me home in his truck along a bumpy track. I had a slug of rum and a shower and rest and felt much better. Thank God for colleagues and a random stranger." He included a diagram of the place where he had fallen.

That night the men enjoyed port around the fireplace. Brian enjoyed a good "yarn" with them. Barry asked him the next morning, "How come you were able to speak so much last night?" He said: "I had something to say." I wonder if all that excitement stimulated the activity of brain cells related to speech.

When we returned from Morialta we bought a second scooter, for me, so that I could more easily accompany Brian on his trips to the seashore and malls.

October 2004

With great reluctance, I planned a solo trip to Sydney for a three-day business meeting. I left prepared meals for Brian and scheduled some events for him with the Robins. When I returned, I saw that his energy was very low and he had eaten little of what I prepared for him. He said he felt very alone. I will not travel anymore unless he can come with me.

Brian still is able to edit a newsletter but for the most part he is using articles that he has written before. He writes a few e-mails but with many mistakes. When complex issues arise, he asks me to deal with them. I have become his administrative assistant. He walks with a cane,

sometimes unsteadily. His doctor wonders if he has Parkinson's disease. His medications continue to be modified as test results dictate.

Always a great teacher, Brian wanted to lead a favourite seminar on a paper by H. Richard Niebuhr. Rather than his usual engaging manner of dialogue and inquiry, he read certain passages and then signalled with facial expressions and hand gestures for us to comment.

This was a strange and sobering event for me. I realise his traditional teaching style of posing questions has become too difficult.

December 2004

Brian begins to experience major mental confusion. His blood pressure has been high for the last week. He became all fired up about writing up his findings related to a social trends research project. He arose at 3 AM, his favourite writing time. When he finished the last paragraph, mental exhaustion seemed to strike and he moved into a partial dream world. Since then, his speech has been minimal, although his coordination seems unchanged. For ten days he kept little food down. I wondered if he might have the flu. The doctor ordered more blood tests and chuckled with us a bit about someone at age seventy-three having the audacity to work at 3 AM. Brian wrote in his journal, "For two weeks before Christmas I have no energy, no images, and no decisions."

I am so worried about Brian. His foggiess and unpredictability are frightening. I am not sure how to be a wife. When Brian has bad spells, I feel more like a mother. Then at a certain moment, I know I need to shift back to being partner. I feel very weary, lonely and vulnerable.

The only physical issues the doctor is treating are diabetes and high blood pressure. I wish I had a medical background.

Brian urges that we buy ourselves a good stereo system for Christmas. We go to the shop, test the sound in many systems and choose the finest one we can afford. This turns out to be the best gift we could have given to each other at this time.

January 2005

We decided to take our planned trip to Sydney and Port Macquarie to visit Brian's niece and nephews. En route Brian had a bad spell one night in Kings Cross, so I took him to a doctor who suggested that he might need thyroid medication. I asked if we should go home immediately, but she didn't feel it was necessary.

I debated about what we should do. On one hand, I saw that Brian was still acting very strangely, both mentally and physically. On the other, I worried that if we delayed going to his childhood home, Brian might not get the chance to go again. We decided to continue our trip.

February 2005

Dear Joan and Bobby,

In the last few weeks it has become clear that Uncle Brian had a couple of strokes in December and January. They have shown up on a CT scan. I wanted you both to know that when you saw Brian in January he was likely in the midst of having a stroke.

His strokes have affected his communication skills. He has a hard time putting together sentences to speak or write. Every once in a while in the last week or so he has surprised me with a spontaneous sentence. I ask lots of yes and no and multiple choice questions. A bit tricky at times, but usually we figure out what he is trying to tell me. When he speaks, his pronunciation is fine. He reads lots and seems to understand what is going on. He is aware of what I am doing.

He is working with a speech pathologist who is a delightful lady, and he is taking lots of anti-stroke pills. He is amazingly relaxed about the whole thing, perhaps even experiencing a bit of relief at not having to produce one more article!

The doctor and we are still exploring other concerns. Keeping food down is an issue sometimes. Brian enjoys swimming but in the last few weeks, his feet only float in the water. I have to hold them down to help him to stand up. Sometimes he has a rough

time getting out of bed because his balance is dicey. He falls occasionally. These could be signs of Parkinson's or related to the strokes.

He deeply appreciated the time he spent with both of you in Sydney in January and with members of your families. He also got to see an old classmate in Port Macquarie.

*Take care,
Jeanette*

March 2005

We walk together regularly by the sea. Brian carries his walking stick. Sometimes we stop and rest a bit on the Robins' patio that is half way up the hill to our house. By the time we get home, Brian is tired. Listening to classical music on our new stereo system becomes a source of comfort to us both. Our black and white young female cat, Heidi, sits close by. Brian was the one who chose her from the shelter, so they are good mates.

I would describe this as a time of standing on guard; being very much "in the moment"; suffering incurable loneliness and incredible precariousness; and experiencing myself becoming "the rock." These metaphors have helped me acknowledge the deep pain I am experiencing as I encounter Brian's physical fragility and give me a way to embrace the present moment. A major question was raised during the process of my journaling: Is this a six month phenomenon of part time caring for Brian, or is this an "until death do us part" full time caring role? An emerging resolve became clear: I needed additional support to both care for Brian and care for me.

Joined by the Robins, we celebrated the ending of Brian's role as editor of *Edges* magazine. As part of the celebration, Brian Robins acknowledged Brian's tremendous recent workload— creating courses, researching and editing *Edges* and writing books. He also gave him permission to take a Sabbatical, affirming that his body has good wisdom in suggesting this shift is necessary. I constantly remind myself to be sensitive to Brian

as his capacity to communicate begins to return, and as he articulates intuitions and speaks using whole sentences.

On Easter weekend Brian asked to attend Good Friday service and Easter mass. At the Good Friday service, we were reminded that we have been given full permission to bear our own crosses: to carry our own pain. At the Sunday mass the priest blessed us all with new life as he walked through the congregation waving a water-drenched branch over the three hundred worshippers gathered there. Brian was startled at first when drops of water fell on his face, and then he began to quietly chuckle. For me it was a delightful surprise. Following the service we met Sister Gail, who later became a great support to us.



Heidi, our cat

LIFE AND DEATH STRUGGLE

Easter Monday 2005

This evening at about 10 PM Brian and I were lying on our double bed. I had just given him his evening pills and he appeared to be resting well. Suddenly I heard an enormous groan. He seized up, and began to choke and turn blue. Immediately I called the ambulance. An emergency operator guided me over the telephone through the next few moments as we waited for the paramedics. When they arrived, they quickly administered oxygen and took us to Flinders Medical Centre. During the next several hours Brian underwent many tests and awakened off and on. Finally at 6AM he was admitted to the hospital and given a bed in a ward.

During the next few days he began to sit up, eat a bit and receive physiotherapy. I hope he will be going home soon.

April 2005

Today Brian was sitting in a chair as I helped him with his lunch. Suddenly he wanted to get into bed but fell as soon as he stood up. I called for help and rapidly a team of doctors and nurses arrived. I was shunted to another room where I held my breath. Soon a doctor reported that Brian was resting but that during this episode his breathing and heart stopped. He was very weak. The physicians don't know whether he will survive the next twenty-four hours. They moved him to a private room. I called my Adelaide colleagues and we began a vigil. We took turns reading poetry and singing.

Brian was in a semi coma, for the next forty-eight hours. The neurology department begins doing several tests on Brian to see what is happening in his brain. MRI's and EEG's show major damage to his frontal lobe and basil ganglia – the realms of complex, executive thinking and motor coordination. A neurologist talks with me at length about Brian and his intellectual and physical history. He acknowledges that there is nothing that can be done. The damage to his brain is too extensive.

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The hard decisions are now in my lap. Do I let the doctors leave Brian on intravenous support and if so, for how long? Do I put him on a temporary feeding tube and for how long?

I am very aware of the life support debate going on in the USA at this time surrounding the case of Terri Schiavo who has been on IV support and a feeding tube for fourteen years. For seven of those years her husband Michael fought with her parents and then with the government to remove life support. She died just this week when support was removed.

I know Brian so well after thirty-four years of marriage. He has signed a living will and I have a directive for his care. Even in the midst of my agony, I am so grateful that all of those papers are in order.

Now the decisions are squarely in my hands. Brian has never been afraid of dying. He has only been afraid of not living fully every moment he has. What should I do?

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I decide to keep Brian on intravenous fluids for now. He still wakes up occasionally so the doctors and I agree that when he awakens he will be fed pureed food. His swallowing is evaluated regularly by a speech pathologist.

For two weeks, Brian remained in a semi-conscious state. His nephews, Bobby and Bill, came from Sydney to spend a day with him. Vin Underwood and Katrin Ogilvy flew up from Melbourne. And our ICA colleagues arrived from Melbourne, Brisbane and Adelaide. All shared poetry, prayers, jokes and their presence at Brian's bedside. I continued to spend most days there from morning to night. A beautiful peace lily and flowers arrived from folks in Canada. I played relaxation music on our portable stereo. I shared stories about Brian with the staff and invited them to read some of the letters sent from colleagues around the world. *I want them to see Brian as a human being not a semi-conscious blob. I am in a state of prayer without ceasing.*

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Brian Robins wrote about a day he spent with Brian. "Last Friday, Jeanette was physically exhausted and decided to take the day off to recuperate, leaving a small team of colleagues to sit by Brian throughout the day. It was as if Brian said, 'Well, if Jeanette can take the day off, so will I.' He slept a most peaceful sleep throughout the day and night."

On Saturday before I left for the hospital, the staff rang to say that Brian was sitting up, feeding himself and cracking a joke or two with the nurses. They were delighted. When I walked in the door of the ward the doctor asked to speak with me. He said that I would need to decide over the next couple of days whether to take Brian off IV support or allow them to administer a feeding tube. He had eaten so little in the prior two weeks that simply continuing to hydrate him, without giving him calories in some manner, was not going to suffice. My being shuddered, but calmly I asked him, "Have you seen Brian this morning?" "No," he replied. "Well I was told he was awake," I responded to the doctor.

The medical team, quite surprised by this, later acknowledged that his awakening was not due to anything they had done. When Brian reflected on his "waking up" after two weeks of semiconsciousness, he said, "It was the Lord."

Now he wonders what is being asked of him.

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A nurse who writes stories begins to share some of them with Brian. Another delightful nurse now gives him wonderful warm towel baths. Brian sleeps extensively, but awakens to eat a bit several times a day. Occasionally I wheel him in his big hospital chair down to the garden on the ground floor. There we sit and watch the ducks playing in the water and chasing each other. The sun shines in and there is the sound of water flowing down the rocks.

I am grateful for this time alone with Brian and yet I am also tense because I worry that something might go wrong.

When I look at Brian I see fragility. Yet I also see relaxation and contentment. None of these words typically describe the man I have known for the last thirty-four years. In fact he has been the opposite: strong, bold, determined, and driven. Yet this new side is not totally unknown to me. I realise that I have been privy to these qualities in unguarded, intimate moments. Now they are evident for all to experience. The doctors look at him sometimes and say, "Indeed, this is a strange fellow!" And I smile. That I have known for a very long time!

Brian speaks only rarely, but enjoys letters we read to him from around the world and the music I play whenever I am at the hospital. He is very attentive to visitors. He may seem to be asleep but as soon as a visitor enters the room he is awake and ready for the poetry and jokes and eager to hear the news of daily life they share.

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After being in the hospital for about four weeks, Brian is ready to go home. I know this because he keeps trying to get out of bed even in the middle of the night. If no one is there, he goes over the bedrail and falls on the floor because his legs lack the strength to support him. The hospital ends up assigning a person to sit near his bed at night.

What should I do? I am frightened. The hospital doesn't think he should go home. They don't think I can take care of him. I don't think I can care for him either but somehow I must.

Once I make the firm commitment to bring Brian home, the doctors put me through a quick but inclusive caregiver training program. The nurses show me how to bathe and toilet Brian. The physiotherapists walk with us and share their insights and techniques. I talk with the speech pathologists about his swallowing issues and what to watch for. A dietician helps me plan a soft diet and gives me vitamin supplements. His erratic swallowing is the most frightening condition of all. I experience being tested and wonder whether I will pass. I remember my vow: *For better for worse, I do.*

Emily, my niece from Ontario, Canada arranges to come to Australia to be with Brian and me. We know her well from her visits to our former home in

Toronto. I breathe a deep sigh of relief and say, "Yes. Now I see how I will be able to bring Brian home. With Emily there, I can do it." Katrin Ogilvy also will be available whenever I need her. I am deeply reassured.

My hairdresser, Sue, talked about caring for her ill and dying mother. Her words of wisdom offered me strength: "This is the most precious time in both of your lives. Treasure this time together."

The social worker at the hospital connected me to home services for showers, transport, food and respite care. An occupational therapist brought Brian home for a one-hour visit. She identified the equipment needed for his safety – a hospital bed and the appropriate walking and bathing aids –and they were delivered and set up in our home. Brian's brief visit to our home after so many weeks away makes him more determined than ever that he is coming home to stay. He keeps checking me out with his eyes to make sure I am not going to renege. He is now relying on me to carry out his wishes.

The doctors expressed concern about Brian's weak swallowing reflex and the high risk of aspirating food or saliva into the lungs. They conducted a barium swallow test to record how food is moving from his mouth to the oesophagus. The results would determine whether he could go home. Brian gathered up all of his tenuous energy and passed the test, much to his delight and that of his speech pathologist. The next morning Brian arrived home – six weeks after entering the hospital.

This is a powerfully told story. It brought me to tears several times while reading it. I think anyone can relate to this journey.

Duncan Holmes, Facilitator

Toronto, Canada

ADVENTURES WITH STRENGTH, WEAKNESS, FRAGILITY AND DELIGHT

May 2005

Going home

During the first weeks after Brian returns home, caregivers visit twice a day to bathe him in the morning and to get him ready for bed in the evening. Other specialists come during the day. It feels as if our home has now become a public place with so many strangers coming and going.

In the midst of this time of anxiety, Amanda Healy, the care worker who assists Brian with his morning shower offers us cheer. She asks questions. She wants to get to know the man she helps each day. Brian's face lights up when he sees Amanda. She gives him hand and foot massages. He shares pictures, books and music. On many occasions she stays well beyond her allotted hours. When her scheduled public home care weeks expire, we are able to hire her privately. Over the year Amanda becomes another partner in caring for Brian.

Movement, falls and zany behaviour

This is the first and only e-mail Brian sent following his return home from Flinders Hospital.

22/5/05

Dear friends and colleagues,

I'm out of hospital after six weeks and back home. A big thank you for everyone who prayed or sent me greetings. I'm able to do more every day, sometimes under protest from my wife and nurses! (They think I may fall.)

Brian Stanfield

In 1995 Brian had written the following poem that captures his love of movement.

Cycling

My wife loves bicycling,
For her it is a way to really see up close,
Not through panes of glass, or haze of exhausts,
but immediately; she cycles to see the
grass, trees, flowers, hills, valleys, gorges, rivers
what's going on, who's growing what;
Her near accidents come
when she sees a peach or magnolia in full bloom:
I, riding behind her can hear her gasp of wonder,
and see her bike wobble, heading for the ditch;
As, she turns away, she exclaims, "Oh Brian, did you see it! Isn't it
gorgeous."

I cycle for the sake of the movement through space,
the thrum of the tires, the wind in the face.
Looking straight ahead, I estimate the gradients
Anticipate the change of gears, thrill to the increase
in rotation. She is thrilled with the sights. I thrill
to the experience of riding cadence. Jeanette's invitation:
"Let's get out and see what's there."
Mine: "Let's go for a ride!"

Brian Stanfield Toronto, 1995

Ten years later, however, Brian's continued love of movement is tempered by the danger of falling. Imbalance and small seizures caused by the strokes heighten the risk. As he begins to feel stronger he suddenly pops up and starts walking. I run to help him go wherever he is going – usually to the bathroom. While Emily is here, she and I are able to lift him up from the floor when he falls. We worry most about him injuring his head.

For as long as I have known Brian, he has had a tendency to fall off bicycles and other contraptions due to sheer zest for movement.



*Brian the biker in Canada; Brian on scooter in Australia.
The continuing mantra: "Let's Hit the Road".*

Fortunately he never got hurt. He told me he just let go and relaxed. Then he would get back up quickly and easily. It worked for him, given his short stocky build. His lifelong ability to fall gracefully came in handy for him over the next year. He felt he could risk more and he did. For his caregivers, including me, it became a nightmare. One moment all was calm; the next he was up and often within moments had fallen to the floor. At this point, however, he could no longer pop back up, even with a little help. Several times I had to call for the ambulance paramedics to pick him up and put him back in his chair or bed.

To compound this reality, Brian could move very quickly when he wished. Shopping trips with him had always been a source of frustration for me. In the past when we entered a large store together, I would lose track of him in minutes. As short as he was, he could walk around the store and I couldn't see him. I would get increasingly irritated trying to locate him. I soon learned that if we decided in advance exactly what we planned to purchase, I could eventually find the aisle where Brian had already arrived. Brian's delight with movement and his zany behavior attracted me to him from the beginning. I remember watching him climb up onto a table and do a dance like Zorba the Greek in the midst of an intense breakfast meeting. I fell in love on the spot. Ever the teacher, he had decided that particular morning that the session needed enlivening. His students recall him standing on tables so he could write on the top of a large blackboard. At less than five feet in height, Brian compensated by standing on whatever was handy to make his impact.

Max, a Brother from the De La Salle teaching order, recalled Brian's mischievous side: "I remember that you, Brian, were always an early bird and I was sluggish in the morning. I asked you to make sure I was awake early. You would knock on my door. Several times you used a water pistol to wake me up!"

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Finally I realised I am caring for a medically fragile man who continues to love motion, risk and making mischief. In the past Brian had prudently considered risks and executed movement carefully. However, severe damage to his frontal lobe seriously compromised his capacity to judge and act responsibly. Usually he is relaxed and a delight to be with – that is until determination strikes and Brian as “the man on the move” takes over. I am disconcerted by the way traits that Brian always had in the past are now intensified and become manifest out of normal context. In the past I could get on with my activities and my life while he was engaged in his own pursuits. Suddenly I have to be attentive to his every physical change, movement, and need.

Losing the ability to read, write, and speak

For seventy years, Brian's identity was entwined with his reading, writing and speaking abilities. In his sixties and early seventies, he often spent ten to fifteen hours a day on a computer conducting research and writing. He was never a big casual conversationalist, but he could hold a class spellbound. It was his short one-sentence zingers that startled and cared for many people over the years: "Brian Stanfield specials," his colleagues called them. He was a fanatic about the proper use of the English language and his vocabulary was always spectacular. He was a voracious reader and loved to locate thought-provoking books. His handwriting, a legible, flowing script was always a source of pride.

Now he makes scribbles that only occasionally resemble a word. All of his former intellectual abilities are significantly diminished. And yet he seems so relaxed. It is as if he were on vacation and enjoying every moment, as long as he is at home in a safe, familiar place and with people he

trusts. His gestures, motions, and facial expressions become his main communication tools.

Patricia, his speech pathologist decided to work more intensely on his speaking skills. She sent him to a Talkback Group once a week where lots of informal conversation is encouraged amongst people with stroke and brain injuries. At least half of the participants were men. After spending time with so many female caregivers, this was a fine change for Brian. He joined right in. A volunteer transported him to and from the session, without my accompaniment for the first time in months. Patricia also conducted an assessment of his cognitive function and noted significant improvement since his previous assessment. He seems to be processing communication much more quickly. I wonder if there is hope for some sort of recovery.

Yet whenever I look at my husband, the only image I see is that of radical fragility. This is not my picture of Brian for the last thirty-five years. He was forever my indomitable, loveable, spirit giant, as strong as an ox. Now he is still loveable and a bit mischievous, which either delights or worries his caregivers. For me, it feels as if all his protective shields have disappeared. I now must protect him from negative energy and physical or psychological danger; I must nurture him with positive energy. I find this is an overwhelming task. I must guard and feed his unique spirit. I must create the environment in which he can be at peace with himself and freely express his quirks and delights. I am the one to select the TV shows and music. I decide what people will surround him. I create his schedule in such a way that it cares for him and me. I read him his favourite poetry, give him favourite foods, and take him on outings. I help his caregivers to know him as a person, not just an anonymous client. As they learn to read his face and motions they know that a lively, albeit now relatively silent human being is in their midst.

Walking and outings

We take each day as it comes. Music, meditation and books with wonderful photographs are very important enhancements each day. I have arranged two photo displays of colleagues from around the world

where he can be reminded of his global community. Sometimes he sleeps most of the day. When his sodium is too low, his coordination is seriously compromised. Other times he can move along with his walker, supported by a steady hand at his back.

Some days Brian is set on taking an outing to the sea or a movie, to the bookstore at the mall, or to visit the Robins. At such times we get moving quickly, for now is the only time he has. His determination emerges unpredictably. He became insistent about going shopping for my birthday gift. Accompanied by the Robins, he went to several stores before he finally found what he was looking for: a beautiful pair of gold and silver earrings. This trip was quite an adventure for all involved with my Brian moving his walker rapidly around the mall while Brian and Rhonda attempted to keep up with him. He spent exactly what funds he had, forty dollars, and came home very pleased with himself.

A man at his Talkback Group is a pilot and a member of the Aldinga pilot's organisation. He arranged an outing for the group to a small regional airport and the opportunity for a flight in a four-seat plane over the beautiful Gulf of St. Vincent and the Adelaide Hills. Brian was eager to do this despite recent hospital stays with pneumonia. We lifted him from a wheelchair into the plane for a great adventure. Then after his flight, in spite of exhaustion, he refused to leave until I had my chance to go up in the plane too.

Celebrating

On 4 July 2005 we celebrated our thirty-fifth wedding anniversary and Brian's seventy-fourth birthday. We gathered in our living room with the Robins, Oakleys, Amanda Healy, and our neighbour, Trish. We enjoyed a lovely chocolate, whipped cream and raspberry jam cake, spicy savouries from the Chinese shop and champagne. A beautiful bouquet of flowers arrived from my brothers in Illinois to mark the occasion. Brian sat in his comfortable lift chair and participated fully.

Last April I would never have imagined us celebrating our 35th anniversary, given Brian's condition, so I find myself abundantly grateful for this "miraculous event".

Food

A speech pathologist comes every few weeks to help Brian with his swallowing. This week she suggests taking one bite and then putting the spoon down until he has swallowed everything. The task of triggering his swallow is very difficult. I realise we usually trust our bodies to perform such automatic functions without a second thought for most of our lives. It is a major challenge and very tiring for Brian to focus intensely and purposefully on swallowing each bite. He usually sleeps for at least half an hour after every meal. As his coach in the process, I feel as exhausted as he.

Brian quickly becomes disenchanted with pureed food. He longs to see what meat, vegetables, bread actually look like and to taste them in their recognisable form. I show him small amounts of meat and veggies, and then mash them up on his plate. Meals on Wheels provides his main meal each day – real Aussie meals. Brian has not enjoyed much "home cooking" since he married his American wife and lived in countries other than his homeland. It is good that some of those tasty treats from childhood are available once again.



On the road again.

Incontinence

Something happens to you when you finds yourself toileting your husband. Once Brian was independent; now he is dependent. Before I was spouse; now I am caregiver as well as spouse. It is a shock to the system. The marriage promise to care “for better, for worse” takes on new meaning.

I recall the day in 2000 when I first was called upon to help my mother use the toilet. It was as if a switch had been snapped on. I was being asked to be a mother to my own mother. I might be sixty years old but I wondered, “Am I ready for this?” Then I told myself, “Grow up, Jeanette. Grow up and fast!”

Brian had a urinary catheter most of the time he was in the hospital. When he first arrived home without the catheter he preferred to wear underwear, rather than incontinence pads. He was still trying to be independent. He made it to the toilet successfully some of the time but not always. This resulted in a lot of laundry. At night, Brian's incontinence was taxing for me. I slept right next to his hospital bed. As soon as I heard him moving, I knew I must get up very quickly and help him to the bathroom. This trip usually occurred around three in the morning. I learned how to go back to sleep quickly as soon as he was settled again. I am grateful that he had good control of his bowels.

This pattern continued until a later bout with pneumonia in October 2005 when his urge to run to the toilet subsided. Thereafter, Brian became quite happy using incontinence underwear. We facilitated dryness, dignity and comfort the best we could. In some ways this became an easier time for me because I was able to get a full night of sleep and Brian had fewer falls.

Caring for myself

I find the sea cares for me. Even if a care worker comes in for a half hour to give Brian a shower, I am off to the sea for refreshment and distance. The sea never ceases to amaze me with its endless surprises. Its far horizons seem to connect me with my family and friends around the world. My lower back is a major physical vulnerability so I am offering it

considerable attention with respect and exercise to make sure I am able to continue caring for Brian at home. I swim once a week on Tuesday afternoon when a respite person is here to care for Brian for four hours. My back relaxes and the pain lessens.

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Katrin Ogilvy cared for me as she played the role she whimsically called *Omniscient Observer* and sometimes took over for me and insisted I take time out. She wrote about this:

“When Brian and Jeanette returned to Australia I was excited, looking forward to engaging get-togethers, where I would participate in their life of intellectual endeavours, the rich culture they embodied and where I would, from time to time, be invited to their home full of books and pictures and ornaments, good food and good conversations. I was fortunate during the next three years to share with them and the many other close friends and colleagues the richness of life even if we lived in different cities in Australia and had grown up in so many other locations on the globe.

At the same time as I enjoyed visits with Brian and Jeanette, I knew that Brian was not well. He had diabetes and at times had little energy. I am a diabetic and was able to give Jeanette some hints about appropriate food for Brian. That was the beginning of a role I grew into as an *Omniscient Observer* among those who were Brian's “Just checking on Ya” caregivers. Most of us get anxious and lose heart around illness and death. It is difficult to say how anxious I was but somehow I didn't lose heart. Looking back now I see that I decided to be “always available.” Although we lived in different cities, I told Jeanette that I expected to be called whenever she needed me. That worked. I appeared relaxed, keeping any qualms under control.

As we can never know what is coming next, I found it helpful to ask other health professionals and caregivers, “What might happen if...?” I especially watched what was happening with Brian in the moment. I had considerable experience serving others in crisis situations, and knew I could keep calm and give in to the shakes later. I found that being clear about what I could and could not do, know and be is a helpful skill.

As an Omniscient Observer I had to be able to step forward and back, come and go, and to live my own life. I feel very honoured that I was there.”

Being supported by others

Emily spent two months with us. She gave Brian a lot of showers and took him on great outings like running him down the hill to the sea in his wheelchair and back up again. They laughed all the way.

Emily later wrote, “Our little outings to the sea are what I enjoyed the most – and I think so did Uncle Brian. However despite my best efforts at pushing that wheelchair, my legs could never move fast enough to truly satisfy Uncle Brian’s need for ‘speed’. (And I don’t think that even the world’s fastest man alive would have been able to do this either.) He never stopped pushing the limits of what great joys life could give. “

Emily was the one who earlier connected us with the wonderfully supportive Meals on Wheels organisation located just up the street from where we lived. Sister Gail and a priest came regularly with anointing rituals and communion. At a celebration at the Robins’ home many Adelaide colleagues gathered together to celebrate Brian’s return home.

Once Emily returned to North America, it was my task to help Brian shower and dress several mornings a week. My back was hurting and I decided to see a chiropractor again.

Short lived strength

August 2005

Duncan Holmes, colleague and friend from Toronto, came to visit us for two weeks. Before Duncan arrived Brian scribbled the word CAR on a note pad. I asked, “Do you want Duncan to hire a car?” His response was a big nod and smile, indicating he was already anticipating an adventure!

Brian and Duncan set out together on the first morning of the visit. Brian navigated the drive out along the southern beaches and then back via a



Oh to pilot my own ship!

favourite restaurant where they enjoyed morning tea. I had no idea Brian would remember how to find these places but by trial and error and finger pointing, he succeeded, much to his delight.

Katrin joined us on a trip to the Flinders Ranges for a few days, up to Wilpena Pound, which I think is the most isolated place one can find in a short distance from our home. I worried that if we needed the services of a hospital, we would probably have to fly out. I suppressed this fear; and we had a great time!

The second day at Wilpena Pound we travelled with a small group into the hills up along high ridges. Brian was enthralled and insisted upon getting out at each stop to see everything. At lunchtime we stopped for a barbecue in the bush. I prudently packed all the “right” food for Brian, but the aromas of the food our guide was grilling were far more enticing. Brian walked around the “barbie” pit longingly looking at the meats and veggies cooking. Nothing could distract him. When the food was ready, I asked him to sit down on a rock near me and promised him some barbecue.

I selected the smallest and most tender bits. While Katrin and Duncan watched from a distance, ready to come to the rescue if necessary, Brian proceeded to eat. I dreaded the thought that he might choke or have a seizure, but at the same time was delighted to see him eat the food well and with great pride and pleasure. It is as if his fully focused energy allowed him to swallow food he hadn't been able to enjoy for months.

Later his speech pathologist approved his eating soft but recognisable meats and vegetables. This ability continued for several weeks.

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We took Duncan up to one of our favourite wildlife spots: Cleland Wild Life Park. In a journal entry at least a decade before, Brian wrote about his first encounter with an emu at this park.

“An emu, a large flightless bird, roughly the size of an ostrich, padded round the enclosure, it seemed to give me permission to approach, so I got really close. It was about my height, so before long we were eyeball to eyeball. I found myself peering into that emu’s eye—it seemed like it was three inches across, and wild of aspect. The emu’s eye seemed to be looking straight through me. I realised I was in awe so thick I’d have to dust it away afterwards. The emu seemed to be saying, ‘I know you through and through, old fellah.’ I had to break off the contact. It was eerie.”

This time we ambled with Brian and his walker all around the park viewing the kangaroos and wallabies moving amongst us and enjoying the koala bears perched in the trees.

And then an emu came into view.

I watched Brian intently to see what he would do. Suddenly he left his walker on the sidewalk and marched twenty feet over to the emu. A woman standing nearby offered him some seeds for feeding the bird. Brian proceeded to eye the emu and then began to feed him.

I held my breath, hoping he wouldn't fall right onto Mr. Emu. Duncan calmly went to the other side of the park to snap some pictures. I moved very quietly toward Brian planning to steady him if needed. After what seemed to be forever, the emu turned away and I reached quickly to steady Brian.

Apparently, Brian had experienced what he had come for: to connect once more with that mysterious bird. Now he was exhausted. We encouraged him to sit on a bench for a bit and then moved very slowly to the exit.

Over the years Brian collected many pictures of his colleagues from across Australia and the world. His photos were in an envelope in a desk drawer. One day during this period, he began to hunt for them in order to arrange them on his photo boards. He began to cut out pictures with scissors that I doubted he would ever be able to manipulate again. He used pins to post the pictures methodically and carefully. Meanwhile, we,



Brian and Mr. Emu: the inspiration for “Just Checkin’ on Ya”.

his caregivers, watched and assisted him as unobtrusively as possible. It was as if parts of his brain that had been inaccessible to him for many months suddenly became accessible. Once he arranged the photos, we hung the montage in the living room, and Brian settled back at rest.

The journey goes on and on

I beg you to lead a life worthy of your calling. Accept life with all humility and patience, making allowances for one another because you love one another.

Ephesians 4:2

October 2005

Dear Family and Colleagues,

Brian had a rough two weeks with pneumonia and seizures but should be out of hospital tomorrow. He is very weak but still he laughs with the nurses and visitors whenever the chance arises. His lungs are now clear. In the last few weeks he lost considerable strength and dexterity in his right side. Now he is beginning to recover the use of his right leg and right hand.

Tomorrow is the Melbourne Cup- the great costume parade of "Down Under" where the world stops for five minutes as the big horse race happens. I will wear my wild purple hat to the hospital to celebrate in the ward. The nurses and volunteers are making funny hats for the patients to wear. Then if all goes as planned, Brian will come home with me.

We have to move at the end of November. I have decided that because Brian is changing so much in his strength and coordination level that I need a caregiver close at hand. Amanda Healey has agreed to create a two family home with us. In the last couple of days we have found a place. We will move on November 28th to Seaford, just five kilometers from here. We will live in a two-story house on the esplanade. Amanda and her two children Sarah and Brandon will live on the first floor and we will be on the ground floor. Brian and I will have less room, but it will be a good compact space in which to more easily care for him.

Brian loves the sea and we will be across the road from the Gulf of St Vincent so it will be easy to take him for a walk or a wheelchair ride along the seawall. Children, surfers, bike riders will be around. And the sunsets will be spectacular.

*Love,
Jeanette*

November 2005

For two weeks Brian is in respite care at a nursing home. This causes a minor crisis of spirit but enables me to complete the packing and moving to set up our new residence before he comes home on December 5th. Brian has always been the master packer so this is a new challenge for me.

A two-week stay in a nursing home can be disconcerting, but Brian went willingly. I am sure that in the back of his mind he worried that I might leave him there for good. I tried to visit him every day but it was difficult, as moving our residence demanded almost all my energy.

Brian entered the nursing centre using his walker to move about, smiling and able to swallow, all signs that he was totally relaxed. The facility was lovely. However, he was given more freedom and unsupervised time than he had enjoyed for a while. He was unable to speak easily or make requests, so with his usual determination, he went right ahead and did things on his own. Unfortunately, I had mentioned to him that the centre might be a good place to strengthen his walking skills in preparation for walks near the sea when he returned home. He accepted that possibility as a serious plan and began walking alone in the long wide halls of the centre. All too often he fell, was rescued and then scolded. He was also reprimanded for wetting his bed, something over which he had little control. After a week he told me he was "grounded" (not allowed out of his chair) although the staff said this was not the case. However, by that time his body had seized up in tension and when he left the nursing home, he was unable to walk or swallow anything.

He glared at the world and me.

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Amanda and I took him to our new home. We showed him his lift chair from which he could view the sea. The remote control for the TV was ready for his use. We took him into the bedroom where his bed, pictures and clothes were waiting for him.

On the wall at the end of his bed hung a special photo of his friend the Emu. Right above the photo Katrin added the caption:

Just Checkin' on Ya

Brian gazed about, while Heidi, our cat, followed us around. Later we sat together at the table. With tears in my eyes, I told Brian that I understood if he was ready to let go now. It was his decision. I felt he had gone through so much.

He just sat while I got him some juice. He drank one sip at a time. Slowly his energy began to return and the twinkle in his eyes reappeared.

December 2005

We are settling into our new home. It is good to have Amanda so close at hand with her expertise and care. I realise that caring for Brian now is a spirit journey for her as well as for me. She calls him "a real gentleman." With funds provided by some of Brian's former students, I am able to pay Amanda to be with Brian more hours each week. Whenever she is there, I know Brian's spirit will thrive. There will be laughter and empathy.

During the October hospitalisation, Amanda realised that Brian deserved a better way to communicate. "Nods and facial expressions don't seem adequate," she insisted. "He needs to be able to share his feelings and wishes with a physical sign. So I asked him if 'thumbs up' is ok? He nodded, 'Yes, it is'. And thumbs down? 'Yes'. His happiness and crossness, yes and no can now be communicated with whatever energy he can muster. He will be in charge of at least a little bit of his life again!"

On days when I am unable to lift him out of his chair, Amanda comes to the rescue. We both learn a lot together about how to trigger his swallow so that he can actually eat the food that he puts in his mouth. One day when I

am having difficulty helping Brian swallow his pills, Amanda suggests that I give him the medication separate from any food. Brian looks at me and nods. He then proceeds to swallow the crushed pills easily.

Later he surprises me and speaks: "Amanda is right".

Over many morning teas, Amanda and I get to know one another and we share our discoveries about how best to care for Brian. She invites me to go to a movie entitled "In Her Shoes". It is about two sisters who are very different from one another but stick together through thick and thin. Amanda and I are now very much like those two sisters even though I am old enough to be her mother.



Kevin Balm visiting Brian, early June, 2006.

I eagerly read Jeanette's story, having admired from afar how she cared for Brian in his final phase of life. Her story contributes significantly to illuminating a part of the human journey we are reluctant to discuss.

*Kevin Balm, Leadership Trainer
Bangkok, Thailand*

Christmas 2005

I reflect on our past research and writing on the role of the elders in our society, and recall a play Brian and I performed with friends two years ago that focused on the possibility of being an active senior.

Brian celebrated this possibility in one of his poems:

Old People and Seniors

There are seniors, and there are old people.
Let these distinctions stand for as long as this poem lasts.
Seniors can be fun to be with: although somewhat wizened,
They are witty, a constant surprise,
And they have lived long enough not to give a damn
About what you or others may think.
If they don't like you, or what you're doing,
They will, refreshingly, say so.

Old people are a different matter: many seem to have given up
On the life force, and you can see the life force
Giving up on them. Their skin hangs on them in porous folds
The spirit leaking out with every breath.

I want to be a senior
– Don't get me wrong: I'm clear about the ashes;
But till I die, I want to live as a senior;
And I'll have my wrinkles;
But I want to wear my age
As a veteran his medals.

Brian Stanfield, Toronto 1996

Becoming Primary Caregiver

Brian has now moved into the next phase of being an Elder and I have become his primary caregiver.

§§§§§§§§§§

Katrin wrote about this next phase:

"Since our previous research on being active elders, we have been reminded that there is another aspect to being an elder. As our bodies change, we learn anew what is possible and what is now being asked of us. This is the phase of those whose minds and bodies have signalled not so much that 'all is not well' but 'all is not young' and therefore 'all doesn't work as it had'. Here a different understanding and learning is beginning to take place. The lifelong search for who we are takes on new dimensions. The lifelong 'exercise' of what we can do becomes a moment-by-moment challenge. The lifelong yearning to be an authentic human being deepens.

Some of us are standing by to assist these undertakings in others. We learn and teach each other to be healers, to bring open attitudes to the struggle for a new independence. We watch the health professionals and learn their tricks of the trade. We learn to lift without doing our own back in. We are walking at the edge of the abyss in a new way. We shake with uncertainties and tremble with hope. We are stretched, but not beyond our limits as we are aware of each other, of our age, our bodies, our physical boundaries and our unique mental and spiritual possibilities. This next phase - as yet unnamed - needs consideration for further learning. "

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I realise that Brian and I are certainly living this next "unnamed" phase. It continues to amaze me that in spite of all he has lost, he is still very much my husband, Brian, in his being. I know this man deeply as I have never known another. I am in touch with his psyche, his soul. I am closer to him than I ever have been and in more deep and intimate communication with him than I ever imagined possible.

This doesn't mean that I do not tremble at times. I do. I have never encountered such constant fragility twenty-four hours a day. His falls and choking terrify me. I wonder, "Today, will he or will he not be able to swallow the pills that I have crushed for him? Which foods will he be able to eat? Which won't go down? How many hours will I spend today getting him to eat one cup of

nutritious food? Will I have to call the ambulance today? And for how many more years or months will I be doing this?"

This latter is the most daunting question.

I have put most of the rest of my life on hold except a few ongoing projects that keep me related to a wider world of concern. This opportunity to accompany Brian is too important a time to miss, even for a few moments. My hours are focused on whatever moments are left with my beloved one. Since every activity for Brian has slowed down, my life has slowed down, too, and we dwell together in the time of one step at a time, one mouthful every two to three minutes. We are in a strange kind of peace. At the same time we are conscious that we are both on an unknown adventure and have chosen to live it fully. All around us people come and go, supporting us in so many ways with services, advice, expertise, friendship, funds, equipment, rituals, music, letters, flowers, laughter, respite, concern, and humor. Our cat, Heidi, keeps watch and provides cuddles and enthusiastic meows. The sea is a constant and comforting presence.

New Year's Day 2006

The task of care giving seems to be getting more and more difficult. The only foods Brian is now able to ingest are nutritional drink supplements, cold sweet foods like cheesecake, puddings, milk shakes and bananas. Getting him onto the toilet or out of a chair is sometimes impossible for me. I have to make sure I get him into bed early in the evening when he is still strong enough and awake enough to help in the process of moving from chair to wheelchair to bed. Because of this concern I sometimes have to end a TV show prematurely, much to Brian's dismay.

I decide that I need to create more objectivity for myself around these day-to-day care giving activities and so I craft some new resolutions:

My Resolutions: I remind myself that I can't live Brian's life.

- 1. I can't take his pills. He decides about his pills. I enable him to take them by crushing them into the easiest form. Then he swallows them or he doesn't.*

- 2. I prepare food for Brian. I help him to eat it but he decides what he eats and what he swallows.*

- 3. I give him as safe an environment as I can. However he still takes the consequences of his surprise actions, which often cause him to fall.*

- 4. I do activities with him but mostly he has to entertain himself in his chair or bed.*

- 5. He is still himself. He lives his life. I live mine.*

And I remember and recommit to a resolve I made in 2005 when Brian became critically ill:

I will make no decisions, act in no way that I am not willing to live with for the rest of my life.

During this past year this 2005 resolve has prevented me from making expedient but short-sighted decisions.

5 January 2006

The Institute of Cultural Affairs scheduled a gathering on Kangaroo Island. Brian is keen to go and see his colleagues again. I am uneasy. The meeting place in a National Park is only a few hours away but it involves taking a ferry and having rustic accommodations in a place that is a long distance from hospitals and health care providers. I know I will not be able to take him there on my own. Amanda agrees to drive us and care for Brian during the meetings.

Upon arriving at a farmstead veranda where friends gather for the ICA meeting, Brian is glowing and smiling as he moves from person to person, greeting each and drinking a bit of wine in the process. We are all proud that we are actually there. At the end of the day, Brian experiences a small seizure, recovers and eventually goes to sleep exhausted but happy.

One night while on the island, we drive fifteen kilometres on unpaved roads to a restaurant for a group celebration. It is a fine event! Brian is

unable to swallow much but as soon as a bush band begins to play his whole focus is on the beat. He dances in his wheelchair with Amanda at his side. His face lights up. I quickly eat a bit of food and then join the fun. At one point Brian tries to get out of his seat so Amanda holds him from the front and I support him from behind and for a minute or two we all dance together. At midnight, Brian is totally alert and remains so until the band packs up and leaves. His delight in this event is so overwhelming that I am sure all the logistical challenges of bringing him to Kangaroo Island were worth it.

Sunday as we are driving home, we run into bush fires on the way to the ferry and are stopped from travelling further. A caring volunteer fireman finds us a suitable place to stay for the night. We are able to get passage on the ferry at 8:30 the next morning. Amanda and I heave huge sighs of relief as we drive onto the mainland. Brian is still aglow from all these adventures.

February 2006

I wrote this note to Brian's caregivers:

"I want to thank you for taking Brian on such great trips over the past weeks. They care for him in so many important ways. However, Brian doesn't need a big trip every week. The Onkaparinga River down the road fascinates him. A wheelchair ride along the sea is also very fine. Even sitting outside in the front or back yard is great. Do what you feel up to, as well as what you feel he is up to."

March 2006

I reflect on my first thirty-five years of marriage. For those years I walked in step with my husband, Brian. People saw us as a family team in our work and in our personal activities. However, since 2005, Brian's strokes and seizures put him into what I would call "a presencing state". He definitely projects the presence of Brian and no other. Yet, he is cut off from significant knowing and doing. He relies on me to provide the environment in which he can continue to be this unique "Brian presence."

At the same time I see that my life is one of knowing, doing and being. My journey continues on, but now without the knowing and

doing of Brian Stanfield. I must be about my own knowing and doing. For years I counted on, trusted and depended upon Brian's gifted intellect and ability to perform important accomplishments. Now I must know, do and be on my own.

In a dream last night I envisioned Brian as an old man like my mother in her nineties.

It is getting physically more difficult for me to take care of him. His right side is weaker. I am having a hard time helping him into a comfortable position in his chair. The effort to get him up from his chair and onto and off the toilet is becoming more dangerous for both of us. I may have hurt his back when I tried to lift him this morning. At night I repeatedly massage his legs because I know they are uncomfortable. My back is in constant pain. I don't know how much longer I can continue to do this. Over the last few days I have had to call Amanda several different times to help me shift Brian's position.

April 2006

Brian is now totally incontinent. He appears to have pain in his body when eating. He experiences uncontrollable bowel movements. I think we are moving into another stage.

One morning Brian was alone in the bedroom. The care worker was cleaning up the bathroom from his shower and his speech pathologist was waiting for us in the living room. I had just come into the bedroom. Suddenly in one of his rare moments of energy, Brian shut the bedroom door and took me in his arms. We hugged and hugged. I wept tears of joy and sorrow, while I held him for dear life, afraid that he would collapse at any moment.

The memory of that hug is now at the core of the overwhelming joy and sadness of that time. I experienced guilt that I had not made more occasions to sit in the same chair with Brian or sleep in the same bed. Fear blocked me most of the time. I didn't think I had the strength to lift him out of a sofa or a double bed. I counted on lifts and hospital beds to do those things for me but they created a physical separation that I now regret. But I am

deeply grateful that, in spite of everything we faced together, our all-encompassing hug healed us, and gave us courage and confidence to face the next stage of the journey.

16 April 2006

Katrin called to say she will come on April 28th to help for a week. During that time I will take a three-day retreat up in the Adelaide Hills to rest and have some reflective time. I am emotionally and physically exhausted. Some dental work on a broken tooth has been an extra drain on my system. My hands are chapped and itchy right now from all the laundry I have been doing. Keeping them dry for a few days should help.

24 April 2006

In a rare, sudden moment of clarity, Brian makes a list of things he wants: shaving cream and a bicycle! Amanda takes him to get the shaving cream and then helps him sit outside to watch Brandon her son ride his bicycle.

Last Monday the Robins and Oakleys took us on an outing to the Botanical Gardens in Adelaide. It was raining. We bundled Brian up and with difficulty got him in and out of the car and then into his wheelchair. He had a great time as Barry Oakley pushed him rapidly through the rain to his favourite café for potato wedges.

Ben Crocker, Brian's godchild, sent a note to Brian, "I still have that long wooden cobra snake that you gave me when I was a boy in Chicago. When my sons ask me about it, they learn about you and how special a godfather can be". Tears of delight well up in Brian's eyes.

30 April 2006

It is Sunday morning. Katrin is here with us. Brian has slipped into a semi-coma and feels feverish. I call the home care nurse. She insists that we take him to the hospital. I advocate that Brian be admitted to our local community hospital, rather than to Flinders that is forty-five minutes away. She arranges for the ambulance and contacts the hospital.

Once in the emergency room, Brian is put on an IV line and antibiotics to treat a urinary infection. As Katrin and I stand beside his bed, the nurses

begin to insert a catheter. Suddenly a "fountain" erupts, the catheter cap is ejected and pure gold urine flows out all over the bed. The nurses jump back. We all watch trying to suppress our chuckles. Later I joined Katrin in a fit of laughter. I know Brian would certainly have joined in the hilarity over such a sight if he had been able.

May 2006

Nestled on my rock with my favourite cliff behind me and the sea below, I wrote this poem:

Cry Jeanette, cry
For all you have lost. For all that Brian has lost.
Let sadness flow. Let weariness flow. Let loneliness be your friend.
Cry Jeanette, cry.
For the being that is Brian. For the being that you are becoming.
Weep for what could have been. Weep, weep, and let life all out.
Be with the tears, pain, emptiness that will never go away.
Let the mask down just for a few moments.
In this silent solitary place Cry, Cry, Cry for Being itself is crying.
Being itself is weeping with you.
Weep, but do not despair. Weep now.
All of creation weeps with you.

7 May 2006

Dear Duncan,

Brian went into Noarlunga hospital last Sunday with a high fever and in semi-coma. He was diagnosed with a urinary infection. Antibiotics and IV hydration drip brought his temperature down within hours and he was communicating with us again.

Now doctors have discovered a staph infection in his blood so he will receive strong antibiotics for another couple of weeks. Brian is relaxed in this hospital— a community hospital where nurses have a little time for old fashioned nursing. He is alert and eating bites of puddings, fruit purees and yoghurt.

Amanda is with him today so I have a rare day home alone.

While Katrin was here I went up into the Adelaide Hills for two nights for some rest and recreation. I walked in Belair National Park where there are birds of all sorts. I walked out on a pier by a lake and ducklings surrounded me! Of course they were looking for people food - even out there in Aussie bushland. I also had some time to write and reflect on the last horrific year.

We took Brian out of the ward yesterday for a little birthday party for Rhonda Robins. He had a bit of cheesecake in the lounge of hospital and thoroughly enjoyed the event.

The doctors say the antibiotics are taking effect and he may be released early next week so we will see.

*Take care,
Jeanette*

15 May 2006

Dear Katrin,

I am feeling a bit of angst at the moment about Brian and all his infections. The doctor is giving him blood thinners intravenously to help prevent blood clots. He is not moving around much so they are taking precautions. He ate well yesterday but didn't want to do any physiotherapy. Amanda will be at the hospital today and then I will be there tomorrow.

I hope you had a good trip home.

*Peace,
Jeanette*

17 May 2006

Dear Katrin,

Brian is still in hospital with big swallowing difficulties and occasional fevers. He ate well until last Friday. Then hospital staff removed the IV line and he got weaker and his swallowing got much worse over

the weekend. The veins in his arms were too weak to accommodate the IV line. Now he is back on hydration support through his stomach. All his antibiotics are now administered orally and he must take so many pills— all day long. I give him some of his medications and Amanda and I help him eat a bit of food. It takes forever for him to finish a meal. The nurses are trying to learn secrets from Amanda and me on how to trigger his swallow.

The Robins and I are meeting with the palliative care team and the doctors tomorrow to decide next steps. One option for dealing with the staph infection is to send him to Flinders for a few hours to insert a tube to administer medications and fluid intravenously for another two weeks. This trip would also involve testing for staph in his heart and elsewhere. The other option is to keep him on oral antibiotics without investigating the cause of the infection further, and sending him home with backup from palliative team and nurses.

Brian's spirit is all right but I think he is tired of having to relate to so many different people. He needs more solitary space and time.

I will let you know what we decide out of that meeting. I feel in need of a bit of colleague support so asked the Robins to be there as well.

*Love,
Jeanette*

19 May 2006

Dear Katrin,

Today the doctor spelled out the situation and his recommendation about Brian's care for the next few days. The palliative care doctor was also present.

First, Brian has been taken off oral antibiotics. His temperature has been normal for twenty-four hours and three blood

samples were clear of infection. He will continue to receive the hydration IV at my request to facilitate his swallowing. The doctor said that the next seventy-two hours are important. If Brian's temperature stays down and he remains alert, then well and good.

If not then we will have to make a decision about more antibiotics and whether to begin an invasive search for the cause of infection. The palliative care doctor told us she did not recommend further antibiotics. Obviously it is still up to us to decide.

I figure that in the next day or so I will know if he is holding his own or not. I will keep you updated on situation.

Sister Gail came and talked with me today and saw Brian. She will pick me up Sunday morning and go to the hospital with me. I am grateful for her presence.

I plan to speak with Brian Saturday about antibiotics. I am doing all right at the moment.

*Peace,
Jeanette*

21-24 May 2006

Throughout Brian's two years of strokes, seizures and infections, I have tried to find ways for him to participate with me in making major decisions about his care.

He was present for the meetings with the hospital doctor and the palliative (hospice) care doctor who recommended that he receive no further antibiotics. Now we need to make our decision.

I know that my best opportunity to talk with Brian about this will be Saturday morning when the hospital ward is usually very quiet and Brian is most awake. The question of continuing antibiotics is really a bigger question: Will we continue to seek further medical treatment?

On Saturday morning, with great trepidation, I join Brian at the hospital. It is quiet, as I had hoped. I know I need his full attention. I look at him straight in the eye and ask him to do a "thumbs up" if we should stop the antibiotics. He takes his right hand and raises his thumb high in the air. I acknowledge that his body is very weak and tell him I will be sad, but ok. I hug him and with tears in my eyes kiss him and give him permission to let go and take the next stage of his journey.

This hospital ward is quite a comfortable place to be so I ask the second question: *Do you want to stay here in the hospital?* And with that right hand he does an emphatic "thumbs down". And when I ask the third question: *Do you want to go home?* His face lights up with a big smile and his right thumb goes up again.

When I arrive at the hospital on Monday morning Brian is dressed, alert, and in high spirits, waiting to go home. The nurses are celebrating with him. Suddenly, what promised to be a very sad moment has become magnificent and I find myself smiling too.

Once at home Brian seems to be withdrawing. He spends all day in bed and takes very little food or drink. He recognises me but seems very far away most of the time.

He is on the hydration IV and has a comfortable air flow mattress. Nurses are coming twice a day and Amanda is here often.

28 May 2006

Dear Duncan,

Brian has been home five days now and is clearly relaxing in bed. Amanda and a nurse gave him a hot towel bath in bed this morning. He is now so fragile that he can no longer receive bed baths without nurses present.

Brian Robins came and read poetry, and we sang together. He gave my Brian permission to take the next step of his journey and assured him that colleagues would care for me. My Brian was

very attentive to this as he was to Gail when she came to share communion. I believe he is intentionally letting go. We are in a mode of watching. Please watch with us.

*Grace and Peace,
Jeanette*

1-3 June 2006

Kevin, a colleague we worked with in India, visited us one afternoon. Afterward he wrote the following note to the global ICA community.

Dear Colleagues

Yesterday I visited with Brian and Jeanette Stanfield in Seaford, South Australia. As some of you may know Brian recently returned from a stint at hospital to what is now a palliative care phase.

Brian was awake and alert to my presence. I read to him some quotes from Gandhi. At one point he took hold of the book, looked at the cover, opened to a page and even attempted to turn the page by himself. While not being able to communicate verbally, his eyes and their movement communicate plenty. Occasionally he'll reach out to hold your hand. While there, colleague Mariam, called from Canada and Brian managed to speak her name.

Jeanette is doing well and approaches this situation in true exemplary style. While being very present to the immediate situation, she also finds ways to care for herself. I am truly amazed at the strength, lucidity and presence Jeanette is bringing to this phase of Brian's life. It was humbling and celebrative to have participated in a small way in such intentional journeying with Brian.

*Regards,
Kevin Balm*

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Margaret Oakley arrived to stay with us for Thursday and Friday nights. What a blessing to have her here. Katrin arrived Saturday evening.

Palliative care nurses come twice a day to bathe, massage, move, and advise. Amanda or I help out. They bring a calm, spirit filled presence and such competence. One young male nurse particularly stands out. He is so gentle with Brian and so caring for his physical body, which is getting stiffer by the moment. Brian gazes upon him with deep gratitude.

These nurses instruct me about when I should get our doctor to prescribe painkillers that they then will administer. For all of these professionals I am most grateful.

7-8 June 2006

Heidi, our cat, sits on the bottom of Brian's bed. On June 7th she leaves that warm spot and shelters in another room with Amanda's cat, Bayles, who suddenly shows up to be her companion.

I reflect that I am sixty-five years old. In that time I have never witnessed the first breath of human life or the last. I cared for children under six months old but never birthed a child. I cared for my mother in her 90s as diabetes and strokes took their toll, but I was not there when she died.

Now I am taking this journey with my husband. Time has stopped. The now is all there is.

The priest comes to administer the last rites. Brian watches him attentively. As one who has traveled this way with others many times before, the priest tells me about the terrain we are now entering. Katrin and I will accompany Brian to the door of the other world. The door will open. Brian will go through. The door will close and we will walk slowly back from that door.

The priest suggests that whenever it seems right during the next hours that I chant a mantra of my choosing quietly at Brian's bedside. I am grateful for the guidance he has offered.

Katrin and I agree that I will sleep in Brian's room until my journey becomes too difficult. Then we will change places.

I awaken at 2:30 AM and sit by Brian. His breathing is a bit laboured but the painkiller that is gently being administered to him seems to be assuaging his bodily pains. I chant quietly: *Glory be to the Father and to the Son and to the Holy Spirit*. Then with tears in my eyes I change places with Katrin who is sleeping in another bedroom. I know that the door is very close at hand.

Brian's breathing softens. Katrin calls me close to 3:30 AM on 8 June 2006. When I get into the bedroom Brian's breathing has stopped. Katrin and I sit beside him. I keep looking at his face. It is calm and yet expressive as though awaiting *the unknown Unknown*. We sit in that silent, awe-filled place until 6:30 AM offering our quiet goodbyes.

Then I call Amanda, the Robins and Oakleys to join us as we had planned. By 8:30 AM we are all together. Around Brian, we pray, remember, cry, laugh, sing, and read poetry. One of the songs, *On a Clear Day*, assumes new meaning for me. We eat breakfast and lunch together. It feels as if we have participated in several funerals and wakes over this six-hour period.

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Amanda reflects on her experience of that week:

"It began to dawn on me that I would be there through Brian's ending time. I know that whenever Brian had been around me, things were good. Am I strong enough? Help me let go. Help me to move forward and be positive about death. In the past I have only experienced pain and hurt at the time of other deaths. Brian looks me in the eye as though to say, 'Yes, you are a strong woman'.

After Brian passed away, I just sat by the bed with his friends. I am secure with these people who love me. Katrin is very special. I hold her hand and feel secure. She has been a great blessing. Without her here this last week things could have been very difficult. We sing the

song *Journey On*. That is important. I feel happy and uplifted. I learn that the end of one's life process can be secure and fulfilling.

I think about how Brian accepted this journey he was on. He didn't hold back. It was as though he said, 'I am here and this is the way it is. Let's go with the flow.' He just let it come to him and lived it fully."

§§§§§§§§§§

Brian Robins reflected as follows on that time:

"Brian was a teacher to the very end. Jeanette says that it was his expressed wish that he die slowly. That was just one of the incredible wishes of his life and I am sure he chose it because he saw that people were not facing death as the last great adventure of life. What we experienced with Brian was a person turning his dying into a teaching experience. What does it mean to have a stroke? We observed that as he lost his ability to speak, to eat, to walk and control his natural functions. And do you know what we saw? A pair of eyes whimsically saying: 'Get clear what we are talking about here'.

I suspect we all wanted to say, 'O God, take him.' But Brian only died when it was time. Several times we had committed him to God, and several times he came back to life to suggest, 'Not yet, not yet'.

Jeanette called us early on the morning Brian died and we came and sat with him. It was as if we were glued there, aware of his presence. It was as if he were saying, 'Look, look, this is the last part, I can't even look now, but I want you to remain awhile yet'."

§§§§§§§§§§

Two palliative care nurses came for the last time. The doctor came to pronounce the death officially and the priest and Sister Gail came to pay their respects. Then at 2:00 PM the funeral director took Brian's body to the funeral home.

His presence remained with us.

POSTLUDE

MOVING ON GENTLY

A time of High Ritual

15 June 2006

Dear Duncan,

The Memorial Service was held here in Seaford. Brian Robins and a priest guided the service.

Twenty-five of us sat in a circle with several small tables in the centre holding items from the four phases of Brian's life: Brian's early years, Brian the Religious, Brian the Teacher, and Brian the Researcher and Writer. Flowers from my family, his former students in the class of 1964/65 and the ICA adorned the room.

When Amanda began to read her poem about Brian, that just about undid me –especially since her daughter, Sarah, sitting next to me, began to cry at that point. But Joan, Brian's niece, and Sarah held my hands and I was able to compose myself and complete my role in the service.

I think the Robins, Oakleys, Katrin, Amanda and I are still in awe. We are walking carefully back from that door.

One great memory I have is of Brandon, Amanda's four-year old. A few days before Brian died, Brandon appeared by himself on the staircase. I asked him what he wanted. He wanted to see Brian so I took him into the bedroom and told Brian he was there. At that point Brian was only able to move his hands and face. Brandon put his hand into Brian's and Brian gave him a big thumbs up. Brandon went around for the next few days singing, "I love Brian!" The night of the memorial service, Amanda, Katrin, Sarah, Brandon and I let helium-filled balloons rise from their balcony. Sarah had written on them, "We love Brian."

On Monday the Robins and Oakleys and I will pick up Brian's ashes from the funeral home. On July 3rd I will go to Port Macquarie with some of the ashes. Katrin will come on the fourth. Joan, Brian's niece will come on the

seventh. On the eighth, with the help of a priest there who was Brian's boyhood chum, we will scatter ashes at the Stanfield family gravesite and on the Hastings River where he had such great adventures as a child. Then Katrin and I will go to the Blue Mountains and stay for a few days.

I haven't been back to the Blue Mountains since Brian and I were courting in 1970.

*Peace,
Jeanette*

26 June 2006

I now have Brian's ashes. The container for the ashes is a tall brown wooden canister made especially by a master woodcarver. How am I going to be able to open it or travel with such an awesome container? It sits in the closet just daring me to come to terms with it.

Sister Gail comes to visit. I show the canister to her. She just picks it up, shakes it and says: "How Brian would laugh at such grandeur!" We chuckle together.

After she leaves, I muster up my courage and set about finding a screwdriver to open the container. I call the Robins and suggest that we scatter a small amount of ashes around the native frangipani tree in their front lawn. Then I get an envelope, open up the canister, reach in and take some ashes and put them in the envelope. Finally I screw the canister closed again. I know now that I will be able to take the ashes with me to Port Macquarie and later to Toronto.

An e-mail arrived from colleagues in Toronto:

Dearest Jeanette,

Praise God from Whom all blessings flow. The Great Spirit has called one of his Warriors home.

Sandra and I grieve with you and celebrate with you the completed life of Brian. It has been a long and arduous battle for both of you and

now he is at peace. We will dearly miss and remember the whimsical, caring, creative human being that Brian was. Brian had a profound impact on so many people around the world, and especially from his years in Toronto. His writings are an enduring testament to his greatness and genius.

Sandra and I are going to suggest to ICA Canada that they establish the Brian Stanfield Memorial Fund as an endowment at ICA. We would also like to suggest to them that you be the one to advise ICA on how the endowment should be used. We hope this meets with your approval.

For you, Jeanette we offer any support that we can from a far distance. You are in our thoughts and prayers. Please call upon us for any need we can provide.

*With love and Grace and Peace,
Sandy and Bob, colleagues from our days in Toronto and Chicago.*

July 2006

On July 3rd I travel to Port Macquarie, NSW where Brian grew up. I want to be there on the fourth. Being anywhere else on Brian's birthday and our anniversary seems intolerable to my being. I will be on my own during the day. Katrin will fly up from Melbourne and meet me in the late afternoon. I decide to take a boat tour on the Hastings River where Brian had many



Jeanette, Amanda, Sarah and Brendon remembering Brian.

an adventure as a child. A rainbow appears over the Hastings to begin the day. I spend a wonderful five hours boating through the everglades in the estuary of the Hastings, Maria and Wilson Rivers. Water dragons, kookaburras and an osprey eagle delight me. A delicious seafood lunch in a wharf restaurant on the Hastings completes the trip. In the evening Katrin and I celebrate quietly over dinner at the town inn. A day I dreaded has become a gift.

During the next few days, Katrin and I take long walks along the seawall and into a rainforest. A boat cruise to Oyster World reveals another dimension of life in Port Macquarie. We enjoy a special meal at a pancake house. Since our apartment overlooks the river and sea, balcony breakfasts become a daily treat and evening sunsets "stop the world". On the seventh, Brian's niece, Joan, joins us from Sydney. Port Macquarie is a hometown for her so she drives us about and shares her favourite spots including a fine café overlooking the river.

July 8th is the day of scattering ashes. We go to the Stanfield family gravesite. There we meet three classmates from Brian's primary school days and two of his former students who have come from Sydney and Brisbane. We share stories and memories, tears and laughter. Brian's classmate who is a priest leads us in prayers. Then I scatter the ashes around the gravesite where Brian's mum, dad and two sisters are buried. It feels as if we are offering a benediction to the whole family.

I scatter the remaining ashes in the Hastings River by the town wharf. We then all head off to the Royal Hotel where Brian grew up and share drinks, snacks and conversation. I am so grateful for this time of sharing and celebrating with people from Brian's life who knew him long before I did. It has been a magical time when the past has come alive again, if only for a moment.

On my return to South Australia, I take things very slowly. I pick up the curriculum design work I was doing, but in a very measured way. Sudden memories throw me into bursts of anguish. Loneliness seems only a heartbeat away. While cutting my hair, my new hairdresser senses my pain and looks in pain himself. When I get home I am in tears. I remind myself to stay with the tears. Weariness becomes my friend. When it hits,

I stop, breathe deeply and read a novel in my comfy bed. The spirit of the land of Australia beckons and I decide to stay another year in this place that is healing me.

I prepare for my trip to North America where I will complete this time of High Ritual.

October 2006

My family came together from California, Colorado and Illinois for a time of reunion and sharing at my brother, Jerry's, home in northern Illinois. It is a very special time for me. I am grateful to be surrounded by kin.

Then it is time to take Brian's remaining ashes to our North American home in Toronto, Canada. A dozen colleagues and my niece, Emily, gather on the shores of Lake Ontario in a bay where Brian and I once rode our bicycles. This was a place we had chosen many years ago for the scattering of our ashes. It was also a place where Brian loved to skip stones. And so all of us had a go at skipping stones – the great, flat ones that abound at that special place. Then we took turns offering Brian's ashes up to the Great Lake.



Jeanette offering Brian's ashes to Lake Ontario, Canada.

One friend commented that we were sending them out across the world.

Later in the week, seventy-five friends and colleagues from Canada and the USA gathered for a memorial service in Toronto. Duncan Holmes, served as our liturgist. Ray, who played cupid when we were courting, was the only authentic, "card-carrying" Aussie present. And there was a mystery guest as well: a black and white cat that entered the side door of the church before the service and sat up in the choir loft. At the end of the service, it departed from the sanctuary in a dignified fashion. Folks who knew Brian's love of cats were delighted.

Mariam shared her experiences of working with Brian in the Human Development schools in Maliwada, India, when she was only eighteen years old. Then after the service, she hosted some forty of us at her home for a lovely Indian meal. Twelve of us remained after dinner, sitting in a circle in her living room, and shared reflections on quality living and dying.

Dear Colleagues,

Joe and I experienced deep refreshment and gratitude this past weekend as we joined with colleagues in Canada to participate in a second celebration of the completed life of R. Brian Stanfield, who has been a beloved spirit presence to our family for almost four decades. Brian and Jeanette, Ben Crocker's godparents, cared for, guided and informed his journey since 1970 when we were all assigned to Sydney together.

Duncan Holmes led a powerful liturgy that included songs; prayers; statements about Brian's four great lifetimes (inspired by Rabindranath Tagore), modelled after the fine celebration that took place in Australia; and witnesses from Brian's longtime colleagues as well as very recent acquaintances, some of whom had only come to know him through his writing. Jeanette's presence for this event and her witness as caregiver to Brian during his last year of life was particularly special.

We were struck by the ever-widening circle of people who have been nurtured/equipped/transformed by Brian's book, The

Courage to Lead and its leadership training extensions offered by ICA: Canada.

Following the service Stan and Mariam hosted an evening of reconnecting – light and serious conversation, hilarious reminiscing and profound reflection. All of this was enhanced by their delightfully gracious presence, lovely home and family, and matchless Indian cuisine.

Jeanette and Heidi hosted us with great love over the weekend. Joe and I drove back to Maine “levitating”—feeling deeply gifted, profoundly moved, and called again to serve.

Thank you, Jeanette, Heidi, Duncan and ICA Canada!

*Grace, peace and love,
Marilyn and Joe, colleagues in Sydney, Australia and Chicago,
Illinois USA.*

With fearless honesty, Jeanette Stanfield details the journey of true life partners in the precious last years of one partner's life on Earth. Having lost my own husband only a year ago, I was touched by the stories and reflections which grace her pages. Her words validated my own experience of care giving, loss, and strange newness of life. Dying time is sacred time and those of us who are able to go through it consciously are immeasurably blessed. Thank you, Jeanette, for sharing your personal map of the mysterious terrain to be crossed at life's end. Brian was lucky to have you checking on him and your book will surely help many others who give care and comfort during this last walk in the human adventure.

*Patricia Webb, Poet and Teacher
Oklahoma City, USA*

REACHING FOR THE NEXT CHAPTER

Since everything in life is but an experience, perfect in being what it is; having nothing to do with good or bad, acceptance or rejection; one may well burst out in laughter.

Long Chen Pa

November 2006

I am home from my travels to North America. Six months of ritual have now ended. I am trying to do some writing but I find it hard going. My shoulders are burdened and I am beginning to know true loneliness. Heidi, our cat, keeps me company.

The poem that Amanda Healey wrote the night Brian died reminds me so much of the many events of the last two years. I will forever stand in deep gratitude for Amanda and her generous accompaniment with us on this journey.

MY JOURNEY WITH BRIAN MAY 2005 TO JUNE 2006

I got a phone call from home care
So I hopped into my car
Following the dotted lines on the road.
Soon the dots fall into one long line
As I fight to be on time.

The wind brushes through my hair
As welcomed I was. The first day went fine.
Hope to see you all next time.
Will be on my way.

Each day went by being welcomed at the door.
I began to know Mr. Stanfield.
The days were going.
Then there was a feeling of not knowing.
Learning about myself.

Knowing I was wanted and needed
Really awakened my self-esteem.

Feeling there is a reason
 For being a part of this man's life.
 Assisting Brian in living his life differently.

The months went by.
 We shared our strength and sense of humour with each other.
 The day we shared the scooter along the beachfront
 Will always be a day that is never to be forgotten.

Many milkshakes and cheesecakes we had
 Brian would insist no matter what
 The sharing and caring that happened
 With both the highs and lows.

I began to watch the mottoes we had.
 "Slowly but surely
 Tell that brain to swallow that food
 Right down that drain."
 All the thumbs-up I received,
 The massages I gave.

Tears and laughter,
 The holiday we had,
 The days we read
 And the games we played
 Memories that will never be forgotten.

I do as much as I can
 Be as patient as I can be.
 Twice I have seen your eyes tell me you weren't happy,
 But as we worked together
 We began to be happy again.

The time has come where I really look back,
 Appreciate all the days we have had.
 You are a different character than I,
 But as I look through that:
 We are all the same.

Now is the time where I learn
 To help as much as I can,
 Holding your hand,
 Trying to hold my head high.

I am proud.
 It has been a joy being around you,
 The night we listened to the music,
 Danced under the stars
 Along with your very good friends
 And your lovely wife Jeanette.

The bond had begun between us all.
 My children have learned
 That people can give to each other in many ways.
 It makes our hearts feel good,
 As I believe Brian Stanfield is all good and
 Very intelligent.

If my son was to grow like Brian has,
 I would be proud.
 As Brian is proud, strong and mischievous
 In his own way.
 But who am I to say?
 I guess I want to be that way!

Each day you look into my eyes now,
 I see you say: It's time to let me rest.
 I will feel when the time is right
 As the sign will shine bright.

Let me have and keep all the memory
 Now is the time I say good-bye to you.
 May you be placed in my heart.
 I will share my love for you,
 The days we had.

By Amanda Healey

23 December 2006

I am in Melbourne, staying with Katrin over Christmas. Amanda called me in the middle of the night to say that Heidi, our cat was hit by a car and is dead. How my tears flow. I feel like Job. Katrin reminds me that endings often come in threes. My mother died on Dec 25, 2003; Brian on June 8, 2006; and now Heidi.

January 2007

I travelled to the Red Centre of Australia last week with a friend who was visiting from Toronto. Our guide, an Aboriginal elder, was sitting on a log near Uluru (Ayres Rock). Suddenly I recalled sitting with Brian at that same spot in 2005 and falling off the log. The memory was so vivid it stopped me in my tracks.

February 2007

It is Valentine's Day. I am sitting on my favourite rock looking out at a gently surfing sea. The seagulls are flying overhead. The cliffs to the north and south are shining in the fresh air. I begin singing the love song, *I Don't Know Why, I Love You Like I Do*. I remember a time when Brian and I rode our bicycles along Lake Ontario. On Saturdays we would ride for hours. We were in our fifties and sixties. I remember last Valentine's Day. Brian and his caregiver bought me a red rose bush. It still sits in a pot outside my front door. New green leaves are growing on it right now. Over the year it has bloomed several times, even once at Christmas.

March 2007

It has been almost nine months now since Brian died and my old world came to a halt. My rational self has shifted into the next chapter full speed ahead. I agreed to take on the role of President of the ICA: Australia network for a two-year term. I enjoy the challenges and interaction with colleagues via email, phone calls and gatherings.

However, my body and emotions are not always that sure. They move to support my rational decisions and then, seemingly out of the blue, halt me in my tracks. My interior being says, "Stop, retreat, rest, find quiet for a little while. I am still feeling the effects of the anxiety and fragility of the past few years. Slow down a bit." I want to avoid

loneliness by being with people, but I wear out quickly and retreat back to my safe, familiar bedroom where drawings, poetry, gentle music, yellow painted walls, a cosy bed and comforting books care for my being. Then I emerge a while later, as if from a cocoon, to be the butterfly again. Sometimes at the very moment I find myself excited, pleased, challenged, suddenly the sinking feeling strikes again. My safe place calls me back again. I am reminded, "Jeanette you are still going through a grieving and healing process. Be mindful. Take care. Give time for your soul to catch up."

My relationship with other people has subtly shifted. I am becoming more open, able to listen to diverse perspectives without becoming defensive. People share deep experiences with me without my asking. My creative insights are more available to me. I am often in a calm place in the midst of storms all around. I am going with the flow. I am obeying my body signals and starting to enjoy "being me" in my space. I shut off feelings of indignation, just noting the event and carrying on. I have been wounded so deeply by endings that other hurts seem to slide off me like water running over soap. All differences seem trivial and not worth the trouble. I am levelled by fragility and endings.

This is a new experience for which I am grateful.

April 2007

On TV last night, Tony Robinson, British writer and broadcaster, focussed on people in the process of dying, both in nursing homes and in their own homes. His report occasioned my further reflection and journaling.

It is the sacredness of the dying time that must be at the forefront of all care structures and practices for those in their ending days. Assisted living is different from this. When one needs help with basic tasks around the house or care centre but can make decisions and interact with others, he is still in charge of his own life.

The dying time is different. It is more like the birthing time. It is when one relies on external, loving care to journey one safely

– physically, emotionally and spiritually – right up to the door to the Other World. The healing professionals help play this role and family members with support can learn to take on aspects of this role.

Anyone given the gift and agony of accompanying a loved one on this final journey is changed by the awe and dread of that ending time. One's being is notched forever. Ending times need seasoned professionals but more than that they need the love and deep honouring of Being itself. This is a time of profound ritual– a stopping time, a sacred moment. How much poorer we are as a society if we ignore, hide, or bury such a time in the busyness of bureaucracy when what is needed is that we stand present to the sacred silence.

I would not have missed the last two years of Brian's life for anything. It was as though I stood on tiptoe the whole time, being present to the wonder and pain of the unknown. When Brian was in hospital and I couldn't be with him at night, I was often anxious, even though I knew I needed some good sleep and relaxation so that I would be ready for him when he came home again. It was his spirit I was anxious about. When he came home, physical care was sometimes difficult but I knew his spirit was being cared for and peace and well-being would come to both of us again.

May 2007

I took the train down to Melbourne and it was about eight hours late. In the long journey my hips and back got out of alignment and are now screaming with pain. I am spending a few days in bed at Katrin's home. Early one morning I had a very vivid dream. When I awakened I knew what I needed to do: remove my wedding ring. So I took it off. In Feb 2006 I recognised that I was on my own relative to my knowing and doing. Now I must let go of my dependence on Brian's presence so I can carry on with being me. I know I will always be greatly enriched by his presence but I cannot be dependent upon it.

Now after three days, I put my ring on again.

June 2007

The Robins, Oakleys and I stand near the frangipani tree around which we scattered ashes many months ago. Brian and Rhonda put a wooden emu in the circle. It looks at the ground. It seems as if the emu and Brian are in conversation.

I have just moved back to Christies Beach. For the first time in my life I will live by myself. The community is welcoming me home.

September 2007

Marcia, my cousin, and her husband, Mike, come to stay with me in my Christies Beach home. Having relatives here is good. This place has again been embraced by my genetic family. All is well.

May 2008

Brandon and Amanda come for a visit. Brandon now a six year old is trying to remember that time when he was four. He looks at me and says: "You were married to Brian." I nod my head. "Are you still married to him?" I hesitate and then say, "He died but he will always be part of me." He continues, "And your cat was Heidi. She was a friend of Bayles our cat." I nod again. "They both died", he announces. "Do you think the three of

Jeanette's memoir is a testament to the painful, universal experience of losing a loved one and is also a witness to the unexpected gift that results in fully embracing human life, even through death. She poignantly illustrates the classic stages of the grief process that both she and Brian experienced – from denial to acceptance – albeit at very different times, as is usually the case. Brian's life was always lived in the context of community – family, religious order, collegial networks – and it was only fitting that his dying also unfolded in the presence of loving community. Thanks to the palliative care movement, this opportunity was made possible.

*Benjamin Crocker, Primary Care Physician
Boston, USA*

them are together?" I smile and visualise the three of them. I respond, "Yes, perhaps."

I come across a poem Brian wrote a decade ago, and wonder what he would add to it now.

Ah, death you are a tricky one,
Taking us when we least expect it,
Letting the ill get better just enough
To expect more of life,
Then cutting them off unexpectedly.
Do you get a kick out of that?

Ah, death, you are an unjust one,
letting some live to term,
to enjoy a second but powerless childhood
and cutting others off in the prime
Coming ready or not, with no back answer,
When all is vision and passion
But not for death: you get a charge out of that?

Ah, death, you are the merciful one,
Our lust to live forever hits the wall.
Declaring a terminus to all our cares,
Cessation to all our striving,
Ah, death, you are good and part of life,
It's you that puts the zest into the business of living

Brian Stanfield Toronto 1998

June 2008

It is now two years since Brian died. I know now what I only suspected before. Brian is a presence for me that can never be taken away. The "eternal now" knows no beginning or ending.

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EPILOGUE

The months of caring for Brian taught me a number of lessons that I would like to share with others facing this journey of accompanying a loved one in his or her process of dying. I am sure each experience is unique, but perhaps some of my insights can be generalised and have relevance and meaning beyond my experience.

Encountering Endings Together

Realizing that the loved one is in the dying process The doctors didn't expect Brian to come out of the coma he entered in March 2005. I remained close to him singing, playing music and reading poetry as the doctors, nurses and close friends came and went. Silence became my friend. No words were necessary as I acknowledged the dying process.

Not knowing how long the dying process will be

The birth process for human beings is usually quite predictable- about nine months. The dying process could be moments, days, months or years. When Brian awakened from the coma the doctors said he could live a few days or up to fifteen years with minimal speech, cognition or mobility. He and I lived with that awareness of his life's fragility every moment of the next fourteen months.

Encountering physical loss Things Brian could do quite easily yesterday he is unable to undertake safely or at all today. I found myself always on guard, watching. I increasingly assumed personal tasks as his physical functions broke down. Sadness kept swelling up in both of us as Brian's many gifts faded.

Letting go As the dying process continues, it becomes necessary to set aside past assumptions about what the loved one can do or understand. I let old expectations go and embraced with gratitude my Brian as he was, not as he had been.

Beholding new capacities If patiently nurtured, the intuitive capacities of a loved one may become stronger as more rational abilities diminish.

Be open to this. As Brian's caregiver I experienced solitude, strange gratitude and sorrow all mingled together.

Protecting Self-hood and Journey of Loved One

Taking charge of care

Make the health system work for the loved one. Have the enduring power of attorney in place and clear care directives signed. Read up on everything you can that informs you about options. Pump people for information about available services. Talk with doctors about options. Get trained as necessary by nurses or other caregivers.

Operate out of gratefulness for the professionals in hospitals and in home support services. This stance helps to create an environment in which your loved one will get good service and you will be given lots of helpful tips.

Try to put the services in place for the next stage of the dying process before that stage happens. Professionals can help you know what is probable but you usually have to ask. Bring palliative care (hospice) in when the ending time is near, even if the loved one is in hospital or nursing home. The palliative care perspective supports the entire care giving system: you, your loved one, the doctors and nurses. The abilities of many palliative care workers are awesome.

Guiding decision-making

Make care-filled decisions that you can live with in the long term. This became a major guideline for me whenever a decision, choice, request was made of me.

Involve the loved one in critical decisions whenever possible. As Brian's speech and motor skills became more compromised, he increasingly relied on me to share necessary information, to clarify decisions needed and to find ways to get direction from him.

Make decisions on behalf of loved one only when absolutely necessary.

Caring for the spirit

Honour the loved one's unique humanness. The family caregiver knows the personality, gifts, history and struggles of the loved one and cherishes this precious being. She allows the medical professionals and carers to see this "client" or patient as a person with a unique history and life.

Create the environment that is safe for the spirit of the loved one.

Examples include music, paintings, ritual, poetry, meals, conversation, and entertainment. Many functional tasks can often be done by others especially as care needs intensify. In the midst of so many losses, Brian was still Brian – delighting folks, being a mystery man, celebrating life. I had to make sure that he could do the fun, wild things he wanted to do occasionally but safely. I also knew and saw very quickly what an environment of saying "No!" could do to dampen his spirit. A few days under the rule of moralistic care giving left him diminished – unable to swallow and in despair– a condition I learned is frequent in people like Brian who experience severe brain damage.

Choose caregivers wisely. Note strong positive or negative feelings experienced by the loved one as he relates to particular carers and make choices accordingly. Public and private care giving organisations appreciate respectful feedback about who is working for the benefit of the patient.

Invite four or five close family or colleagues to be a part of journey with both of you. Others can play a supporting role to both you and your loved one. Times will get difficult. You will need a person or two you can cry and laugh with and rely upon in small and large ways. Your loved one will also need others with whom to share his struggles and laughter.

Caring for oneself

Don't try to do things beyond your physical, mental and emotional capacity. My lower back has always been a point of physical vulnerability for me. I quickly realised that I would not last very long as a caregiver if I tried to give Brian showers every day. Someone else would have to do that. I also decided that I needed a day to myself each week to be refreshed physically, mentally and emotionally. I found the necessary care respite to make that possible.

Acting as a victim of circumstance hurts both you and your loved one. If your situation does not fully permit you to care for your loved one in your home, then work through alternative care for the well being of you both. You can still play an important role for your loved one.

Pace yourself. Do regular exercise and reflection. Find music, books, poetry, and activities that care for you. Have a few different projects that you keep your hand in, even if you have minimal time and energy for them. Meet with others who are caregivers. Get regular respite from volunteers or paid workers. Attend to your own regular health check ups.

Take time for centring. Find those special places that care for you and centre you. For me it was the sea. It was ever changing and held unbelievable mystery. One rock near our home between a wonderful cliff and the sea became my “safe haven”. It was there where “peace in the now” refreshed me, and after even a few minutes I was able to return calmly to my care giving task.

Give yourself permission to be a family caregiver. This is a task as worthy as any other and perhaps one of those great privileges one does not ask for but is given.

Accept that being a caregiver of a loved one changes you. Be open to the journey of change that happens to you in the midst of this kind of intense caring situation. Allow that change in thinking and action to become a launching pad for the next chapter in your life.

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Jeanette Stanfield

October 2009

Long after Brian had drawn his last breath, there remained pinned to his bedroom wall the photo of an emu with watchful, omniscient and fully present eyes, beneath which was the caption Just Checkin' On Ya. This icon served as a kind of talisman during Brian's last weeks of life, a loving reminder that family and friends were in constant, vigilant accompaniment. As its title suggests, this book is a memoir of the experience of caregivers who engaged in "checking on" and the patient who was getting "checked." Jeanette writes powerfully about her unexpected, exhausting, fearful, fascinating and often humorous journey with Brian during his last two years of life, and then about her first two years alone after his death. Her lessons learned reflect courage and determination, and offer encouragement that each of us can be a caregiver for others.

*Katrin Ogilvy, Retired Rehabilitation Hospital Administrator
Melbourne, Australia*

