



Martin Raffaele

Stepping

a personal journey

from darkness into light

I developed epilepsy due to scar tissue that formed on my left temporal lobe following two periods of complicated febrile convulsions in my first two years of life.

I experienced absence and simple partial seizures during my teenage years, but these were not recognized as seizure activity. At the time it was thought that the auras I was experiencing were occurring due to sinus problems.

It was in my early twenties when I began to experience complex partial seizures. Tests detected the tissue damage caused by those febrile convulsions so many years before and I was finally diagnosed with epilepsy.

Singing was always an important part of my life, and from the age of fifteen I received many scholarships to further my singing studies. However the scholarships discontinued not long after I began to experience regular seizures, and while I had been training and working as a professional singer, the increasing frequency of the seizures forced me to abandon my singing career.

Not having received any epilepsy

education or support, I was unaware that there were any guidelines for living with epilepsy. I believed if I could relax enough and breathe through it, I could control my seizures. The consequences of performing certain actions were incomprehensible, such as swimming alone in the surf. As a result I had a seizure while swimming and drowned. Thankfully a surf lifesaver was on the beach and dragged me from the surf and resuscitated me.

When I regained consciousness I found myself in the Intensive Care unit of Warriewood Hospital. I was told that I had a large amount of sand in my lungs and that I was only alive because my lungs were so well developed due to my intensive singing training. All of this occurred because I had never been told of the dangers of swimming alone.

Over time I have experienced many physical injuries, including a dislocated shoulder, broken foot, falling onto a moving car, falling off a railway platform onto tracks, plus others too numerous to mention, due to my seizures.

Until I was made aware I was eligible to receive a disability pension, I worked at any job I could find. A stint at waiting tables saw me spilling red wine on models dresses while they were attending important gatherings, and dropping trays of glasses and plates due to shaking, a side effect of taking high levels of epilim. Understandably, this career did not last long.

With the lack of understanding in the community I began to withdraw from being involved in social activity. However, I was determined not to allow my condition to control me and in 1997, at the age of 26, began studying at The University of New England.

However I continued to have, on average, seven complex partial seizures a week even though I was taking high levels of a combination of three medications. Surgery was recommended and in 1998 I had a left partial temporal lobectomy.

In 1999, around six months following the operation, I recommenced my studies at the University of Sydney. I had been seizure free but by the June of '99 began, once again, to experience a high level of seizure activity. Further neurological tests were carried out and it was found that the previous surgery had not been completed correctly and I underwent a second partial temporal lobectomy in October, 2000.

I received no support or education following either surgery on the implications of this procedure. It was only my own investigation and the reading of books such as, *The Comprehensive Evaluation and Treatment of Epilepsy* (Steven C. Schachter, Donald L. Schomer), that I became aware of the symptoms and

consequence of a seizure, allowing me to recognise the actions of the pre-ictal and post-ictal period. This knowledge gave me the opportunity to not only recognise and understand why particular emotions are experienced prior to the convulsion, but also an ability to return back to regular activities without emotions such as depression, a factor of the post-ictal period for many, from strongly affecting me.

I purchased the audio recording of a book titled, *Practicing the power of now*, written and read by the author, Eckhart Tolle and listened to this CD series every night as I went to bed. This book was extremely helpful and provided an insight into the personal and social difficulties I was experiencing.

It is unfortunate that epilepsy education services are not readily made available to both a person with epilepsy and those who are closest to them as the onset of epilepsy in adulthood can often lead to a division in relationships and in the family environment.

This lack in knowledge was a strong influence in the separation and ending of my two marriages. It has been these two experiences in combination with the ability to develop a third person perspective when reflecting on them, that I adopted following the reading of Tolle's book. This has enabled me to objectively understand the difficulties that the partner experiences.

The major difficulty that I experienced following the separation in my second marriage in 2003 was the need to depend completely upon myself. This meant walking for 30 minutes to the closest supermarket, and bringing home several bags of groceries by bus on a weekly basis. I was now required to take care

of both myself and the home, including paying the bills and maintaining the home, which was difficult to perform. It was at this time that I began not only to keep a diary to remind me of all the activities I needed to do, but also a journal to understand the emotional difficulties I was experiencing.

Adopting the advice of my mother to keep a journal, writing on a daily basis the actions that I had performed and the emotions I was experiencing, was a great breakthrough after having been through long periods of depression. This action saw me stepping from darkness into the light. I became not only aware of the impact of surgery and seizures on my memory, but also the psychological effects created by the lack of knowledgeable support and this allowed me to recognise the difficulties I was experiencing. In fact it was this need to understand that developed my strength and dedication to continue my studies and offer understanding and education to others.

The two operations, and the periods of recovery saw my Bachelor of Arts (Sociology) degree taking seven and a half years (June 2005) to complete. I began studying a Graduate Diploma in Psychology in the second semester of 2005, and due to the completion of relevant subjects while studying my B.A., I was able to complete this degree at the end of 2006. I began my present degree, the Masters of Philosophy at the beginning of 2007. This two year degree will be completed this year (2008). Following the submission and marking of this research paper I will begin my Doctor of Philosophy (PhD) studies, 2009.

The use of computer programs, such as Kurzweil and Dragon Naturally Speaking, has assisted my academic studies immensely. There have been times in the past when I have been advised by academics and specialists to "forget it all" and find some job in a supermarket. It has been my own beliefs that by achieving these goals I can offer the inspiration for others to attempt to accomplish what seem to be unattainable goal, and also perform academic research on epilepsy, offering knowledge and understanding from an angle that, to this point, has not been shown.

At times I have felt that the hurdles before me were insurmountable, but I have learnt to access help through disability services. During my journey I have had help from some wonderful people, but I had to find my way first before I could start helping others.

As well as studying and singing in the University choir, I also offer support for men who have developed epilepsy as an adult and their families, assisting them to understand the changes that are required to be made, both physically and socially.

I believe that many people have the ability to attain what seem to be impossible dreams if the necessary knowledge and support are readily made available to all concerned.

Martin has chosen epilepsy as the area of study for his thesis and is still recruiting participants for this project. A detailed description of Martin's research project and a call for participants can be found on the following page.