

Denis Strangman reviewed the following book. An excerpt was published in our November 2014 Newsletter. The following is the full review.

“Lemon-Sized Tumour”. Jenny Overton. Even Before Publishing (www.evenbeforepublishing.com) and (<http://www.lemonsizedtumour.com.au>) /123 pps. 2014. ISBN 9781921632976 (p’back).



This is a wonderful book by a Faith-filled mother as she and her family travel with her son from 18 to 25 years of age after he is diagnosed and recovers from a *pilocytic astrocytoma* brain tumour – a so-called “best case tumour”, as she was informed.

It is the story of a brain tumour survivor and his family and is fairly rare within the non-scientific literature of brain tumours because so often the published stories are about someone who has lost their fight or they and their carers are dealing with a more malignant primary brain tumour, such as a *glioblastoma multiforme* (GBM).

Jenny Overton’s journey will provide great insights for the carers of a person newly diagnosed with any one of the 120 different types of brain tumour. She honestly reveals her fears and trepidation and often there is a linkage to passages of the Bible which are relevant to her situation. This is understandable for a woman who was a teenage convert to Christianity and has a deep acceptance of the part that God plays in her life and that of her family.

The Overtons live in northern Tasmania in Australia, near the city of Launceston. Their son Pete - one of four boys and then 18 years of age - was diagnosed with a brain tumour after failing a driving test and an alert optometrist had identified inflammation of the optic nerve.

This is the start of a seven-year journey, involving neurosurgery at the Royal Hobart Hospital (300 kms from home) and periods within its Intensive Care Unit (ICU), High Dependency Unit (HDU) and Rehabilitation Service.

Jenny Overton reveals that Pete had experienced health problems from an early age, including severe migraines as a mid-Primary school student. A visiting specialist assured her he does not have Asperger’s Syndrome, which she had wondered about, but there is no explanation available, until the neurosurgeon suggests his tumour may have been in his brain for at least ten years, judging by its size (like “a small lemon” of 5 cms diameter) and vascularity. Pete’s tumour was located on his brain stem (“tiger country”) and was blocking the ventricles which disperse his cerebrospinal fluid.

After a Registrar explains the significance of a pre-surgery MRI and she and Pete only half absorb what he is saying, Jenny writes: “It is the brain itself that protects us from reality. Like some Machiavellian guardian, it refuses to let us see and believe all the truth of a traumatic

situation such as this. We heard the words and understood the gravity and process of the situation, but denial was the first place our minds would go. Acceptance was another place again, one that was down a long and painful path. It would be a long time until our minds allowed us to reach there”.

This is a common experience by patients and carers, as has been revealed in surveys by Brain Tumour Alliance Australia (www.btaa.org.au) . Only a small proportion of the initial clinical explanation is retained or understood.

Following his original surgery Pete has a bleed in his right temporal lobe and subsequently has left-side paralysis. He is kept in a medically-induced coma to allow the swelling in his brain to subside. Jenny writes of her helplessness and anguish: “As Pete’s body lay hooked up to so many machines, I pondered where Peter really was. I had a strong visual sense that he was submerged in some still, deep and dark pool in a wood between the worlds. I wished I could pop on a magic ring and be taken to that place too. I desperately wanted to be with him, but he was somewhere I couldn’t be; somewhere I had to accept he must be. Only God was there with him. I tried to imagine that God was there, holding him and singing him a lullaby”.

Pete eventually wakes up: “Yesterday, there had been nothing but an emptiness in his eyes and body, but today there was something more; there was a spark of life”.

On the outside Jenny is holding it together but on the inside she could not reconcile what was happening: “Didn’t they (the hospital staff) know this was my son? Didn’t they know my life was falling apart? Why did they talk to me as if I was a sane and rational woman? I felt like a farce. I should have been screaming and running down the corridors wailing, or sobbing in a corner somewhere. Why didn’t someone give me a hand-out called *Ten Things You Must do as a Parent in this Situation?* Number one should have been: ‘have your nervous breakdown during the first week, but please do it off hospital grounds and duration should be one hour only’.”

Pete develops meningitis from an infection – a not uncommon occurrence that carers often only learn about when their loved one deteriorates post-surgery. After new surgery to replace the tubing attached to his brain Pete tells his mother he thought he was going to die.

The Overtons receive practical and spiritual support from a number of people, including those from their own community and internationally who are praying for Pete’s recovery.

In 2002 this reviewer created a prayer-request website to receive requests for prayers from brain tumour patients and their carers. It received thousands of requests from around the world which were redirected to the Yarra Bay Eucharistic Prayer Community in Sydney. In these situations prayer can become a source of hope, regardless of the strength of one’s faith, or even lack of it. In a popular contemporary television series in Australia there is a scene where a woman who is diagnosed with a familial breast cancer gene is shown lighting a candle in a Church. TV producers often have a good grasp of what happens in real life.

One of the friends who supports Jenny is Sallyanne, who coordinates a hamper of meals which are brought to Hobart by Jenny’s husband when he travels from Launceston each Friday. Another friend is Tracey from Hobart, where Jenny is trapped while Pete is in hospital. Tracey asks if there is anything she wants and Jenny responds that she would like

a long, hot shower and hair products and a hair dryer, living as she is away from home and missing those things. Tracey promptly arranges them.

It is simple gestures like these that mean so much. The Social Work department at our local Calvary public hospital once sent an email to all its volunteers asking if those who travel and stay at hotels could donate the unused and unopened soap, hair conditioner and hair shampoo items that are provided as a courtesy to guests. They were making up packages for those who arrive at the hospital with nothing.

Similarly, when Jenny is able to clean Pete's teeth he is ecstatic. The staff could only do that when they were free and they were generally overstretched.

Jenny finds the HDU "a sad, difficult place ... it was like a deep, sad valley in the desert of this world". Later, she writes: "Hospitals are strange places. They are like a micro-universe. They suck you into their vortex and spit you out again when they've finished with you".

Be that as it may, later moving from the neuro ward to rehab "felt strange". "We had trusted so much to the staff there and it was difficult to leave the security and safety of what had been home for many weeks to start up in another place," she writes. Jenny has a similar feeling when Pete is finally discharged from hospital five days before his nineteenth birthday and describes the loss of the support system as probably their biggest adjustment.

In Pete's rehabilitation Jenny is conflicted between being a mother who wishes to be proactive in guiding his path, and letting Pete make his own choices. Pete dramatically does this while still in hospital by asking a nurse to shave his head, which is done. He then comments: "Ha! I look like a hardened criminal now with all those scars over my head!"

Jenny is bargaining with God: "Because of Pete's circumstances I had my own little bargaining sessions with God. We have our ideas about what we can and cannot handle and believe God will work within these guidelines. Surely God is going to fix this now and things must improve? It's the way our minds work, going through various scenarios of what God must do. As Christians, we have faith, but faith can become a veil for denial, or a mandate for the outcome we, with the best of intentions, want".

In the world outside the hospital Pete tries to adjust. He slowly regains his guitar-playing ability but helping out in a coffee shop is a real challenge, from which he disengages. He also finds participation in an IT course too much. Occasional cruel comments by the public about his walking gait are hurtful: "A bit early to be drunk".

Jenny observes that "the neuro teams aren't in the business of assisting with the behavioural and psychology of the aftermath. It's left to the groups: charitable, volunteer and government run. As a carer, I sought out these people to try and find some insight into some of the difficulties I faced. When I eventually found some the relief was enormous".

She found Facebook useful but real support came from a Melbourne-based facility called the "Bouverie Centre" (<http://www.bouverie.org.au/>) which works with families coping with the impact of an Acquired Brain Injury (ABI), among other things. Jenny travelled to Melbourne and had a two-hour session with staff. Knowing that there were other families going through a similar journey "was probably the most helpful thing of all".

Brain Tumour Alliance Australia has also found this from people who contact its Freecall support number 1800 857 221. They are relieved to eventually reach someone who knows what they are going through and often comment: “Why did no one tell me before about your organisation?”

Jenny is cautioned that she must look after her own well being. She resumes quilt-making and enjoys this but at one stage she found herself being intolerant and angered easily. She attributes this to grief and in a powerful analogy writes: “Grief is a strange thing. It can be like a traumatised animal in a lair, and only comes out when it is sure of its safety. You can’t starve it out or force it out, but it will come eventually. Ignoring it will never diminish it. This is why sometimes it can sit for many years, but it is patient and will come”.

How true. For carers of those with a malignant primary brain tumour and a poor prognosis grief can often emerge as “anticipatory grief”, at what might be up ahead. Again, few carers are warned to be aware of this.

For Jenny, Pete and the family “There’s pre-surgery life and post-surgery life”. Their lives have changed. “I used to be a bit of a crier, but now I rarely cry,” she writes. Her husband is now the opposite.

Pete had been given the option of having follow-up MRIs but he chose not to: “I know my body and I know I am well”. He has been finally discharged by his neurosurgeons. He has moved out of home and lives independently and runs a successful on-line store selling fossilised sharks’ teeth!

Jenny writes in the final chapter: “The last seven years have been a gift. It’s been a gift that has taken a lot of difficult unwrapping, but inside are wonderful blessings of gratitude and thankfulness that can be received no other way but this way we’ve travelled. I would not give up what I have gained in the last seven years for any treasure in the world”.

This book is thoroughly recommended for anyone who wants to know more about the impact of a brain tumour and the resultant Acquired Brain Injury on an individual and their family.

Denis Strangman

dstrangman@gmail.com

October 2014