

## **The Broken Bucket**

**(Alison Zander, Year 2 Graduate Entry MB Swansea)**

Leon beckoned the waitress with a wave of his hand. “Excuse me, what song were you singing just then?” The waitress looked surprised at his interest, but engagingly responded, “I was just humming ‘There’s a hole in my bucket’”. Crinkles formed at the sides of Leon’s eyes, “But you were singing an alternative version of that, weren’t you?” The waitress gave him a blank look, and scanned the rest of our faces for clues as to what he meant. Leon continued, “You were singing, ‘There’s a hole in my bottom’”.

There was an awkward pause. I could see the confusion on the waitresses’ face as she glanced from Leon to each of us in turn. It was obvious she had no idea how to react. We needed to take the lead, quickly, to smooth everything over, and help her politely escape from our table.

The trouble with brain tumours is that there isn’t a physical signpost to suggest that there is anything wrong. If one lost a limb, one might have a wheelchair, or a prosthetic arm. If one suffered a major stroke, there may be a facial droop and stiff, weak, arm and leg. These eye catching abnormalities build sympathy in others and change social expectations. With obvious dysfunction, sufferers are often met with patience and any behaviour is accepted without question. The waitress is given no indication of Leon’s brain tumour. There is no way she could expect or understand his quirks. Naturally, she will feel uncomfortable, probably assume that he is weird, and that is unfortunately what we’re going to have to try and deflect, to reduce the stress for everyone. Quickly now, we should react and smooth everything over.

Family meals out are a rare occasion, primarily to avoid a definite awkwardness. Leon gets overwhelmed and confused at the table and invariably makes unusual comments or requests. Having a meal in a restaurant is a lot of social information to process: taking in the sight, smells and sounds of the new room, being shown to a seat where you have never sat before, respond to questions from waiters while absorbed in an extensive menu, making decisions and conversing throughout; this can feel chaotic even with all of your faculties intact. A man missing half of his frontal lobe finds it especially challenging.

Leon’s diagnosis was heralded with unusual signs and symptoms over a long period of time that no one could piece together. As a young man, he was extremely active; a member of the Mountain Rescue team, a Scout Leader, a competitive runner, he revelled in the company of others and always acted the joker of the party. As years passed and his children grew up, his activity levels dropped and his social circle shrunk. He stopped walking home from work, gave up weekly five-a-side football and put on weight. He became set in his ways, having the same breakfast – bananas on toast – every morning without fail. He became stressed about seemingly insignificant things, such as a fly meandering through an open window open on a summer’s day, or the bath mat being wet after a shower. When he wasn’t at work, he would sleep at all hours. My mother thought he was growing old before his time. His friends stopped calling at the house, as he fell asleep when they were there. He became sullen and argumentative, so that even his family avoided

spending time with him. When he started soiling himself, my mother took him to see his GP.

At the GP practice, Leon and my mother sat side by side. Leon was quiet and my mother did all the talking. She described that Leon was always asleep, that he couldn't get to the toilet on time and that his behaviour was odd, in a way that was difficult to describe. He had stopped bathing, wasn't rational and just wasn't himself. He had thrown dirty underpants out of the bathroom window, which had luckily landed on the conservatory roof instead of in the neighbour's garden. The GP responded that he was stressed, advised him to cut out caffeine to help him sleep better at night, and sent him away. Before leaving the doctor's office, Leon was unable to zip up his own coat, so my mother did it for him.

Two weeks later, following a sudden onset headache, vomiting and confusion, we rushed him to hospital where he was admitted for investigations. While awaiting his results, I asked him if he had taken any medication for his headache, Leon thought for a moment and replied, "Yes, I've had 'Quantum of Solace'".

Urgent CT showed a 9cm diameter infiltrating mass in his right frontal lobe, we were told. My mother tearfully signed the surgical consent forms on his behalf. Dad was made nil-by-mouth in preparation for his surgery. The registrar explained what was going to happen; that Dad would be taken to the anaesthetic room and when unconscious would be taken through to the surgeon, who would operate on his head. They would open his skull, assess the tumour, and remove what they could. They considered his chance of survival to be 50%, but if he did not have surgery, he would certainly die. Did my dad have any questions? Just one: "When is the chippy open?" We couldn't tell if it was a deliberate joke, but with our nerves running high, we all broke into uncontrollable laughter.

Of the two people who underwent neurosurgery that day, my dad was the only one who came out. It was the largest tumour the neurosurgeon had seen, a 'museum case', we were told. Following surgery, dad was taken to the High Dependency Unit to recover. As a family, we sat in the visitor's room and two at a time were allowed to his bedside. Mum and my older brother went to see him first. Dad beamed when he saw them both from the other side of the room, and cried when they approached his bed. He hugged my mum as if he had not seen her for years. He described 'waking up for the first time in months'. The room, to him, was vibrantly colourful, and he said he had undergone a 'tsunami of the mind'. On seeing me, he cried with joy, as he couldn't remember the last time he had.

Dad's surgical team were amazed at his swift recovery. We were told the tumour had likely started growing anything up to two decades ago. I was surprised to hear I might not have ever have known my dad as a well man. He was discharged home just two weeks after being admitted.

Dad's positivity towards life was as amazing as it was unexpected. To think you have known someone your entire life and for them to change overnight is beyond bizarre. He was loving, where he had been argumentative. He was awake for 20 hours of the day, where he had been asleep before. He delighted in company and

conversation and my mother said she 'had the man she had married back'. We had hope that my dad was well again and the future looked very bright.

His positivity lasted for as long as he was medicated with steroids, after which, he became sleepy again. This was exacerbated by his course of radiotherapy. With the tiredness came frustration and agitation. He made daily routines and became irritated if they were disrupted. Everything he did was reactionary; waking, dressing because he was cold, eating when he was hungry, and sleeping when he felt tired. Beyond this, he became transfixed by music and the television. He would constantly tap his foot to a song in his head, and conversation became a one-way recounting of a programme he had watched. He was transfixed by things the rest of us tend to pass by. He would stare at the white lines in the sky tracking the former path of an aircraft and the swirl of white milk as it mixes into tea. He commented on a dog playing ball, "I bet that dog is thinking, 'this is a good game'". His nature, though perfectly content, was of a simplified version of his former self. We slowly adapted to the new Leon, carefully navigating his set routines.

Six months' following surgery he returned to work with a bounce in his stride, still rejoicing in his new chance at life. He took boxes of tea, coffee and hot chocolate for his colleagues as a gift, to share and prolong his celebration. He had lost computer skills since being away, and was given one-to-one training to try to get him up to speed. His manager was advised to make adjustments to his day to accommodate his drowsiness. Dad's optimism and determination to be an invigorated success in his workplace slowly ebbed, as his manager's frustration at his low productivity increased. This was notable at home, as dad became quieter and started hiding letters. On finding my dad asleep on the floor of the disabled toilet one afternoon, his manager sent him home for a period of 'gardening leave', despairing that it was unsafe to have him in the office and that they simply did not know what to do with him.

Gardening leave sounds green and pleasant. In reality, Dad had just been 'put out'. Three months' into the leave, he was made redundant. It was a blow to the family, as he had always been the main bread-winner. However, dad was thrilled that he did not have to go back to work. He was free of a significant bind, could help himself to a second breakfast whenever he wanted and spend even more time watching the television. My mum sought work advice from the Macmillan nurses, who said that given his condition, he would be unable to complete a job application form without help, and no longer had the ability to navigate a job interview. We had to accept his early retirement, despite the financial penalties.

My mother and I tried to find support to help both our family and my dad make sense of and improve his condition. We arranged an appointment with a Psychotherapist, who undertook an assessment of my dad's cognitive ability. This showed that his short term memory is very poor, and he cannot read other people's body language. On a positive note, he is still a very intelligent man, can recall detailed information about complex subjects that he is interested in and can mathematically problem solve. The therapist and my dad developed an excellent rapport, and in the few sessions they had she tried to describe both to him and my mother how his condition affects his abilities, what to expect and how to work with them. She described his set-routines as rigid-plans, where other people have flexibility of thought, dad does

not. When he chooses to do something, he sets a plan in advance and goes through it one aspect at a time: he walks to the kitchen, he picks the bread from the cupboard, finds a knife in the drawer, sees the butter in front of him and butters the bread with the knife. If any of the ingredients or tools are not where he expects, he becomes overloaded with information: if there is no knife in the drawer, he has to think of other places that a knife might be; he has to look for the knife in those places; he may have to wash and dry the knife before he uses it. All of these are automatic to anyone else, but overwhelming for someone missing half of their frontal lobe. Dad's reaction is to become frustrated and shout, and our reaction is to berate him for shouting and find him a knife. It was stressful navigating his mood changes. Understanding his limitations and giving him a different perspective on his condition encouraged us to live with him better and to take his outbursts less personally. It also encouraged my dad to accept his limitations, and gain perspective on his condition. He no longer felt that he was 'poorly once, for a short time, while in hospital'; he accepted that he was always going to be limited by the tumour that had affected him.

The more social information that dad has to take in at any one time, the more obvious his limitations are. In one-on-one conversation in a quiet room, giving him space to think, you might not know that anything is wrong with him. However, at any gathering, there are so many people, noises, and decisions to make that he will be unable to follow convention without prompts and guidance. His filters for appropriate behaviour and conversation are not the same as ours, and he will say things without care or understanding of the implications. At family Christmas dinner, he will compare the gravy dish to a toilet bowl. On collecting me from an airport – a significant change in his routine – I complimented him for looking smart, and he responded, "Does that mean you fancy me now?" Certainly not what a daughter ever expects to hear on arrival home.

In the restaurant, there had been so much going on around him; reading the menu, choosing his courses, ordering, people conversing with and around him, that his attention had been drawn towards one thing that he can still process with complete clarity: music. The waitress had been humming and dad's ears had zoned in. Unfortunately, with the background noise, he couldn't quite decipher the words, and with a leap of imagination decided it was a humorous alternative to the original. He wanted to share with the waitress that he knew her joke. So he beckoned her over.

"Excuse me, what song were you singing just then?" The waitress looked surprised at his interest, but engagingly responded, "I was just humming 'There's a hole in my bucket'". Crinkles formed at the sides of Leon's eyes, "But you were singing an alternative version of that, weren't you?" The waitress gave him a blank look, and scanned the rest of our faces for clues as to what he meant. Leon continued, "You were singing, 'There's a hole in my bottom'".

There was an uncomfortable pause, building in anxiety. I could see the confusion on the waitresses' face as she glanced from Leon to each of us in turn. She had no idea how to react, so we needed to smooth things over, quickly.

The whole family burst into hysterical laughter. It was, after all, a very funny joke and dad has a fantastic sense of humour. Dad has endured more change than anyone

should have to with remarkable resilience. He definitely is not weird, he has simply been dealt more difficult cards than the rest of us. The waitress needn't feel uncomfortable, and nor should we.

Now 62 years old, Leon has been tumour-regrowth free for six years. He lives at home with his wife, youngest son and dog. He is happy in his retirement.

*2500 words*

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*Written with permission, with thanks to Leon Zander.*