

## THE LAST THIRTEEN DAYS

This is an account, albeit somewhat disjointed and not journalistically correct, of the last thirteen days of Graham Brown's life as experienced by his wife Ruth. Graham was a pharmacist who had been in practice for some 42 years and until a hip replacement operation on 13<sup>th</sup> May 2004, had shown no real indication of the symptoms which would follow.

On 3<sup>rd</sup> August 2004, Graham was taken to a private hospital in a suburb of Newcastle to undergo a lumbar puncture and any other further investigation into his rapidly deteriorating condition. I will briefly back-track and speak of some of the events that I noted on a pad around the time prior to visits to his doctor around mid July 2004.

When sleeping, fidgets or jerks continually between every 3 to 8 seconds. Occasionally this will be up to 16 seconds. He doesn't remember doing it by morning. Denies level of memory loss and becomes argumentative about keeping locum commitments. Was asked to turn down temperature of urn in kitchen at Church Hall before Church service, started in the direction then apparently became sidetracked and left without doing so. Much steam, not much water left in urn! Generally commanded control of kitchen yet not capable of carrying out a simple request for a cup of coffee. Same at home. Seemed to perceive that he wasn't able to offer much help and was finding this very frustrating.

By the time Graham & I had the first appointment with our G P, his condition was deteriorating before my very eyes day by day. Just as I would realise that a certain procedure would improve tomorrow if I did "such & such", it was too late by "tomorrow". On visiting his G P, some three weeks before being admitted to hospital for tests, he failed a simple quiz when asked to count backwards from 100 by 7's. The he was asked to draw the face of a clock with the hands pointing to twenty past nine. His brilliant mind failed him in completing both these tasks. This consultation was pivotal in the ongoing series of CAT scans, MRI's, MRA's and then the further tests in hospital.

On the evening of 2<sup>nd</sup> August 2004, I had cooked a special meal as I felt this time we had left together was important and would be brief. I talked to him of what he felt, was it frustration, fear of loss of friendships and perhaps being excluded? He said "yes" to all of these

and so I tried to keep the tone of the conversation very positive, reassuring him that, although he had already suffered some brain damage, as the initial tests had shown, we were there together & I would always stay by his side. I had watched a physical healing of the hip replacement from the first few days after the operation but had decidedly noticed a bad pallor, continuing weight loss, lack of energy and, general disinterest and unwell-ness.

The first five days in hospital consisted of a lumbar puncture on day 1 and result on day four (Friday).

Saturday (day 5) brought relatives, friends, business associates from near and far after hearing the shocking news that Graham had fatal brain disease fCJD.

Day 8 (Tuesday). "Sensations" increasingly difficult. Can't get top dentures out. Continually scratching & rubbing face and head. Jerking movements come & go, very tired. Sore, red and watery right eye. Still wobbly on legs – scary when on my own (no nurses around). Last night I slept on mattress on floor – a bit cold but comfortable. Held hands as we "slept" head to toe. Graham wanted to get up once or twice & at one time was very agitated and asked for his neck to be shaved in the middle of the night. I reassured him it wasn't appropriate time of day for shaving and he was fine. Slept pretty well so we did get some sleep. I've stayed with him after first day or so because he was apparently wandering and so it was most upsetting to leave him there on his own and frightened. I'm so tired and trying to pace myself. It's not easy when I have so many things to attend to.

Day 9 – 11/8/04 and Lisa's birthday. This morning we learn that the diagnosis is certainly CJD and whilst we knew, it is so final and devastating. So hard to believe that he's only 63 and six months ago we thought the world was our oyster for at least ten years. Now we make memories and I know most will be sad. We have found that Jack Jenkins (uncle) suffered the same fate but this family hasn't been close to us so we really didn't ever know what he died from. What a pity! By this we know that it is the hereditary type (genetic) very scary and we soon learn that our children have a 50% chance of carrying the gene and 60% chance that it will manifest in them. Since the time of writing this, these statistics have jumped to up to 80%

Day 10 and I have arranged to take Graham to a private hospital close to our home where I hope that, with the help of friends, we can take

him home for a stint through the day but I would be reassured by the medical backup at hospital and sufficient number of nursing staff required to care for him around the clock. I brought Graham on this ½ hour trip in our own car. He did manage to walk 2 or 3 steps from his bed to a wheelchair but from then on he needed to be lifted by 2 strong men to both put him in and get him out of the car at the second hospital. He was never able to walk again and of course didn't get home either. His condition was deteriorating rapidly before our very eyes, as it had been from the very first time we went to visit a doctor. The trip between hospitals was exhausting for Graham and he is much worse, should have been transported by ambulance. He's been eating really well all along. All our girls are here and we enjoy some quality time. Dementia is accelerating at rapid speed but he still tries to speak or ramble. Ate good meal at 5 but as darkness falls (sundown syndrome) things start to happen. The jerks are getting worse and then he starts to hallucinate. The girls are demons and this scares them very much. I try to comfort them. I have been home this morning and had a sleep but now it is getting late and Mandy & Susan will stay with him the night. The deliriums – tremors – jerks & demons are out of control & we know that one person can't manage him. He suffers so much from "sensations" probably associated with much muddled brain messages. Head, back, legs always being scratched. I think severe pain would be better. At least pain killers mostly work. I leave the girls at about 10 to eat and sleep in preparation for what is to come.

Day 11. G.P. has been and Susan and Mandy go home to shower & eat. Earlier we have asked doctor to assist Graham with all necessary pain killers, sedatives etc in order to make him more comfortable. Doctor asks my consent to insert canular to administer all this. Doctor has prescribed a "cocktail" which can be increased progressively. Graham's not eating now and just taking thickened lemonade and receiving water spray etc. We prepare for his body to shut down. The brain is closing down very rapidly. Dr finds rapidity unbelievable – so do we. I think maybe the poor darling hasn't been well for some time. I probably won't get a chance to continue on here but for now – this is the worst day of my life and my heart is breaking. Many visitors again. A former staff member who loved him dearly, has traveled a long way to say goodbye. So emotional, nobody wants to leave as they go through this heartbreaking process. Fr. Roger comes, Peter, Tom, Laura, Jeff, Cooper and Gus, and later in day Pete, Josh & Will. Every family member had opportunity to have a hug goodbye whilst Graham was lucid and aware of this special time. I have an ache from

my throat to the pit of my stomach & I feel as if it is all being torn apart. Close friends keep coming back as does his business partner, Jenny who is like our family. At about 4.00pm nurse inserts subcutaneous procedure and girls & I all watch this. We agree this is necessary in order for him to find peace. Within an hour the jerks and irritability have subsided. He sleeps a while and then wakes & eats custard and apple crumble, ½ a beer and later a sip of wine. Kitchen staff think this request strange but when we suggest it to Graham he nods his head to say “yes” and then wolfs into it briefly. Doesn’t matter, we would give him anything. His (our) friend John arrives and then others come & go. John goes away to get us a bottle of wine. He thinks we deserve it and so do we! More dear friends come & go & Fr. Roger comes back. As our Priest, he has been very supportive in sharing the peace & love that has made this journey so much in tune with our Christian faith, but more than that, through these past weeks he too has become like part of our family and for me, a very special friend. We have sandwiches, wine and happy talk. Graham is getting distressed, Roger leaves and we start singing. Mostly his favourite hymns/choruses and of course love songs. Graham seems to enjoy this. Doctor comes and suggests we should give ½ hourly administration of medication if needed and we agree. Graham immediately becomes much more settled and has a peaceful (mostly) night. I go home again late and get 4 – 5 hours sleep. I know that I need it. Mandy comes with me – I’m concerned about how little sleep the girls are getting too. Lisa stays till 4.30 am and Susan leaves at 6.15 when I arrive back. I hope that they can sleep.

Day 12:

Looking back, I wonder if this dreaded disease may not have moved on to this stage if Graham hadn’t had the hip operation. I have read of another patient dying after a severe trauma. We can’t turn the clock back and obviously that time bomb has been ticking away since birth. I pray that our children will be spared. This morning Graham has had three cups of apple juice and some water, very thirsty. I suspect that he will no longer take solids and now that he’s heavily sedated, I think we should allow him to pass away peacefully. I will ask for two visitors only at one time as it’s been too noisy. More friends come this morning again – some twice a day. Our friend Jeannie minded the baby (Oliver) yesterday afternoon and she will become his other grandmother over days ahead. It’s 9.30am now & Graham is being bathed in water chair. I sit in lounge at hospital and wait. My dear friend Jan has arrived by now & has taken over the running of my house. How blessed I am with all these dear friends around me.

Thursday 19<sup>th</sup> August. Forget how many days but Graham has existed on thickened nectar & water spray – very hard for us all but that is all he can swallow. He had a peaceful night last night but this afternoon has been fit-full – terrors etc but no increase in morphine etc. yet. We are worried about anyone leaving tonight, I can't believe it's one week today since I brought him here. He was previously at the other hospital for 9 days. We have all had some beautiful moments of high emotion with him, speaking of our love etc. We have watched many people come & go, having said goodbye to him. Graham has been fully aware of what is happening all along although this has been highly emotional for him & us.

Friday 20<sup>th</sup> August. This has been Nanna's (my Mother) anniversary and a few days since my aunty Lila's. What a time! Last night was rather peaceful for Graham, I was up and down checking on him. Today I have been emotionally drained with signing papers of consent for a post mortem. I knew this would happen but it's been very difficult as he is still alive. He will donate brain tissue and I pray that this will make a major contribution to the discovery of a cure for this terrible disease. Neurologist came at 8.00am this morning. There was a meeting with the hospital board at this Private Hospital where Graham's hip surgery took place and a code of practice has to be put into place to avoid contamination. In the future people will have to declare if they are known to have this gene etc. Major issues like insurance policies not being renewed etc. It's a minefield. What a dilemma for the authorities I know but there's been so much for me to be aware of and take in that I'm starting to feel overwhelmed. It's like opening a can of worms. I later went to our G.P.'s surgery to sign more papers, blood tests etc and sadly, to give information regarding Funeral Director. I feel like it's asking a lot for us to take this step at this point but then I understand that the weekend is coming up & our doctor is going away. When Graham passes away and the family has a viewing, he will be taken to Glebe where the post mortem will take place and he will later be brought back to James Murray's at Hamilton to await funeral service and cremation. The quick transport to Sydney is vital for early testing. All too much when it's our loved-one we are speaking of. We have jokingly said "trust him to have something really rare and exotic". Poor darling, as if he has had any idea of the possibility of this disease falling on him.

Saturday 21<sup>st</sup> August 2004. I slept at home last night & Susan stayed

with her father “bless her”, she sat up most of the night. He snored very loudly & breathing was laboured. Today he had a visit from a lovely young male nurse by the name of Patrick, who spoke so gently to him yesterday and lo and behold, came again this morning, which is his day off! The spirit had spoken to him to come to Graham and reassure him that Christ was waiting for him and He didn’t want him to be afraid. He told us he was a Christian and I replied that Graham was too. As I expected, when Patrick asked Graham if he was frightened, he replied “no”!

Brian our dear friend arrived last night & was very distressed about his good friend – finds it hard to believe & we all do! I came early this morning & Susan went home for a while only to work, weeding, cleaning, pool etc. Mind therapy I feel. Graham is settled into unconsciousness & not responding to conversations etc. It is now 4.00pm & he has moved occasionally – stiff arms & leg movements. Trouble with swallowing. Dr. says this morning it will be in next few days, I think soon. It has now been 18 days since he first went to hospital. Lisa, Susan & I stay tonight & have a bad few hours till around 1.00am. Weekend agency staff doesn’t understand case and proceed to treat him as “normal” case. We find this difficult and ask for doctor’s orders to be followed up on, which will hopefully result in Graham’s comfort. Treatment not what I had expected at this point of time but with insistence, the nursing staff make his night comfortable & I especially don’t want him to be frightened. After some treatment and siphoning of mucous from lungs, Graham becomes much more settled and sleeps for rest of the night.

Sunday 22<sup>nd</sup> August. He is looking gravely ill and has a raging fever – pneumonia we presume. He had earlier been catheterized as urinary system failed. I think he will leave us in the next 24 hours. Fr. Roger comes in at 11.0am & we have a nice chat about all things & then Holy Communion. It is a special time for our family & Roger remarks how unique we are – we agree. Graham played a major role in establishing loving support within our family. The day staff has arrived by now & thankfully have an acceptance of making the dying as comfortable as possible. Graham labours away at breathing whilst his heart is beating very fast. Mandy returns from Sydney by now. If I haven’t already said this, then I should say that our 3 daughters in order of birth are Susan, Lisa & Mandy. (As I write this chapter, 2 weeks & 4 days have gone since Graham passed away. I hope that I am recalling most of the events but this has been difficult). No more visitors but Roger returns in the evening. As the day progresses we try to cool Graham’s body & by evening, Susan has dishes of water and ice

to keep the cold cloths coming. We seem to get his body cool but his head is like a furnace. It is hard to help a loved one to die, knowing there is no turning back. We attempt to roster ourselves to rest but Susan insists on sitting up & cooling him & kissing him. One by one we join her & at 4.10am, as we lift his head to cool it, he goes to rest. We share this time privately, say prayers, kiss him goodbye & hold him – hold one another and then finally call the staff. They are very comforting and we have a coffee whilst they wash him & prepare for transporting his body to Glebe mortuary for the post mortem. I can't believe this is over and now comes the preparation for the funeral & the grieving. I feel such misery at the thought of life without him.

As I write this, some 13 months have passed since Graham left us. Initially, I could only approach my life day by day as the unexpected road ahead seemed impossible to navigate. I do not like my existence of much aloneness but, with the support & help of friends, family and my church family, my life goes on hopefully & in a positive way. I trust that my existence will be fruitful to me & those whom I encounter, and especially to the cause of supporting the research into CJD & the families who have lost loved ones through this dreaded disease. This account has been literally from my pen as I put my thoughts & our experiences on paper. Forgive me if it seems overdramatic but one's emotions are high at such times.