

To My Husband, John Weepers

6th February, 1944 - 16th August, 1999

I have written this in a type of diary/letter form to John. I felt I needed to (for me) to tell him what happened, as a couple of times while he was suffering with CJD he said to me, "What is wrong with me that you know and aren't telling me?" And I had to tell him, "The doctors and I do not know what is wrong with you."

It is February 2008 and eight years after losing you, my husband John, I feel I should now sit down and look at what I wrote eight years ago of your struggle with CJD. Looking back, the one huge feeling of despair that was hardest to get over and that slowed my recovery through grief and depression, was the missed chance for us to say goodbye. I feel that we were robbed of this when the various doctors could not diagnose you. The main diagnosis was from the head specialist here in Adelaide, who gave you intensive checks and finally told us that you had a very fast progressing and unique form of multiple sclerosis. I remember after he left your room we cried and hugged and said that this we could try and cope with and that at least you would have a number of months still to spend with your family and friends. Little did we know that three weeks later you would pass away.

When I look back and read this diary/letter, it reminds me what a truly huge nightmare we went through. I have not picked up the diary for eight years. Now I am off to a conference in Melbourne on the 17th and 18th May, 2008 and hope that out of all of us who attend someone will be able to help the doctors to better pick up on the symptoms of CJD. I don't want other families to go through the nightmare that you and I, our sons and my parents, by my side through all of this, went through.

I now start your diary/letter:

It is the October long weekend, 1999, and as I sit under the huge red river gum up near our shack at Wall Flat on the River Murray, where we, our family and I, laid your ashes to rest, I reflect back on the nightmare of the last four months, since 21st June, 1999, the day I admitted you to hospital.

I remember that day clearly – and of course the day you left me in your hospital bed at the hospice – but many of the days in between seem a blur. I can remember details but I'm not too clear on when certain things happened.

You were a wonderful, loving husband to me for 27 years and father to our two sons Benjamin and Tom. I am so glad God gave you the chance to see your first grandchild, dear little Bailey.

On May 23rd, 1999 at Benjamin and Tanya's engagement party you were very ill with 'flu. I have never known you to have had 'flu so bad before. You were in bed all day, high temperature, shakes, body aching all over but you got out of bed to go to their party and you helped carry the food that I had been preparing for a couple of days.

That night you started staggering a little and slurring your words slightly; a couple of people made the comment, "Gee, John's very drunk." But you hadn't had anything to drink. You didn't have time with carrying all the food up the stairs and helping Ben and Tanya prepare the room for the guests. Plus you were on antibiotics.

When I look back now, you complained for a while about having trouble seeing. You kept saying you needed to have your eyes checked as you may need new glasses. You were always tired and had headaches.

Then you became rather irritable and snappy and would get your knickers in a knot about small things. You lost your block at our friends and family. This was all completely out of character, you were a quiet man who never caused any argument. Also, you tended to forget things and had to repeat important things over and over.

Over the next four weeks your left arm and leg ached a lot, and you were giddy all the time. When you went to our GP a week or so after the party the doctor said that you had very bad 'flu and your wonkiness was a symptom of that.

On June 8th, 1999, your first grandson Bailey was born. You were not well on that day so I went to the hospital to see Tanya, Ben and Bailey by myself. The next day when you came in, you had to hold my shoulder to steady yourself as you couldn't walk on your own. You said you felt everyone was looking at you thinking you were drunk. You were frightened to hold Bailey, worried you may drop him.

During this period the cricket was televised at night from overseas and you sat up all night, every night, unable to sleep for the pain in your left arm and leg, and the twitching that had started down your left. Sometimes you would doze. You went back to the GP and said you were not getting better, that you'd stopped driving the car about two weeks previously as you didn't feel confident in driving. This was causing a problem as we had our own business to run and you had to be out on the road everyday. On that day the GP and I watched as you held onto the wall, stumbling up the passage from the waiting room to his consulting room.

That day, 17th or 18th June, I drove you to the doctor's and had to help you walk into his room. He took a blood test and made an appointment for you to see an ear, nose and throat specialist. The GP thought you may have had an inner ear infection from the 'flu. I remember the ENT specialist testing you and looking over your head to me, acknowledging that this was something serious. He suggested you'd need to see the neurologist.

During the next few days your co-ordination was terrible. You couldn't package the filter pads for the tap filters into the packets, dropping them all the time. You staggered everywhere and needed to hang onto things to get out of a chair, to walk.

On the Sunday 20th June, in the morning before you were admitted to hospital, you fell out of bed. You sat around all day quite depressed. I remember you crying because you were so depressed and hadn't had a full night's sleep for nearly a month.

On Monday morning 21st June, 1999, I remember you saying, "This is hopeless, me sitting around all the time, I feel useless." I was doing the washing and you wanted to help me so you carried the clothes in a bucket down to the clothesline. I watched you through the window in the laundry: you staggered, like a man who was severely drunk, down to the line, and there you tried with all your might to peg the first piece of clothing on the line. I remember crying as I watched you. You couldn't get the peg to open. You tried several times before giving up. You came inside and started to cry saying, "Something is really wrong with me." Then you got up out of the chair and fell over. And that's when I said, "Right, I am taking you to hospital."

On that day Monday 21st June, 1999, about 11.30am, we walked through the doors of the hospital emergency with you hanging on to me, stumbling everywhere.

In emergency you went through many tests and the doctor in charge said, “We will admit your husband for further tests and the neurologist will see him tonight.”

John, I remember they gave you an admission form to fill out, but your sight was so blurred that I had to fill it in with you verbally answering the questions. When I handed the biro and paper to you to sign I was shocked: you couldn't remember how to sign your name and when you did it wasn't your signature. I went over and told the admitting nurse and she reported this to the doctor in charge.

About 7pm the neurologist came and gave you many tests and asked a lot of questions. I remember him treating you and I and over the next couple of days as if were making it up. It was horrible.

You were in a ward of four beds for over a week. Every day you had physiotherapy, and your determination and will power and sense of humour were wonderful to watch. The staff all admired what you were doing.

During this first week you stopped watching TV as you had blurred and double vision. You saw things on the wall and ceiling that were not what they were. You tried to play cards a few nights after you were admitted but as you couldn't shuffle them or pick them up they ended up all over the floor. You couldn't look at the newspaper or magazines because you couldn't turn the pages, let alone read the writing. You started to grow a beard because you couldn't shave.

The neurologist put you on four to five days of intravenous cortisone but this didn't help at all. On the Sunday nearly a week after you were admitted, you fell out of bed in the early hours of the morning and had to be helped back into bed. That afternoon I was supposed to go to a close friend's wedding, but you were so depressed when you rang me that morning – as you did every morning – that I didn't go. Late that afternoon they moved you to a private room, where you stayed until August 3rd when you were taken by ambulance to the hospice.

Over the next few weeks at the hospital you had so many tests – CT scans, MRI scans, blood tests, eye tests, co-ordination tests.

I remember the day I took you to another hospital for even more tests to be done. I picked you up about 8.30am and wheeled you in the wheelchair down to the car at the front entrance, where a nurse helped me get you into the car. After we left the hospital you wanted a hamburger so you directed me to a nearby shop that made lunches for all the factory and office workers around the area. I must admit you did have trouble finding the place even though you used to go there quite often with deliveries when you worked at Tip Top Bakeries. You sat in the car while I went and got you a hamburger and a can of Coke. I remember I had satays and we sat in the car and ate them. You had great difficulty, the hamburger went everywhere (you had a craving), the Coke you drank with a straw. Then I had to take you back to the hospital – you didn't want to go. I enjoyed this time together on our own, it was very special.

Gradually from then on I dreaded every day going into the hospital as to how I would find you. My darling husband started to change and deteriorate, not weekly but every day. You fell over in the shower and were scrambling around on the floor until a nurse found you in this position, you had black eyes and bruising everywhere. You started having difficulties swallowing. You were also very sensitive to the lights so your room was dimly lit all the time.

At first you were diagnosed by a specialist who said that you had a unique form of fast-progressing M.S.. I had received all the literature from the M.S. Society so at this point we thought we had years ahead of us. But then you started to deteriorate very quickly and the neurologist said there was something seriously wrong. "I think it's a brain tumour," he said. He thought that your immune system had tried to destroy the brain tumour.

Your left arm started twitching more and you were in a lot of pain down your left leg and arm. Then overnight it seemed your arm would wander up in the air and go rigid. I, or my mother or friends, would have to rub all of your arm and tell you to relax, relax and push your arm down. Then it moved into your right side. You would have spasms, fits, every 15 – 20 minutes like electric shocks and I would know when they were coming as you would start twitching.

With the twitching and fits you would bang your arms against the side of the bed. You had bruising all up your arms. Some days I would arrive and you were sleeping more and your whole body would be twitching.

I remember the first Sunday two weeks after you were admitted to hospital, I took you home for lunch. I picked you up about 8.30 am, you were dressed in your tracksuit and using a walking frame. I drove you down to see Ben and Tanya's new house. On the way back home you cried, saying, "I am no good, I can't even help my son when he needs me with his new house."

We had a lovely roast lamb lunch (your favourite) with all the family and you enjoyed a couple of glasses of red wine. Most of the wine ended up over you as you misplaced where your mouth was and also your hand would shake. You had to use both hands with me helping to guide the glass. At this point you were still managing to feed yourself with me cutting up your food. I took you back to the hospital about 3pm. It was a lovely day

You rang me every day or I rang you. I remember the day you rang me crying and needed me. I raced into the hospital. You'd had a terrible night and were so glad to see me. I helped you have a shower on the shower chair, the first time you couldn't manage to shower yourself anymore. The nurse and I settled you in to bed and you finally fell asleep so I went home to get some work done for our son Tom who'd taken over the business.

One morning a lady from the hospital's administration department rang me. "Mrs. Weepers," she said, "your husband has been trying to dial your telephone number. It was showing up on the switchboard with the light flashing on and off – we thought it was a child playing around with the telephone so I came up. Your husband was quite distressed he could not remember the number nor hold the phone to dial it." Hence no more phone calls after this.

I took you home again the next week for lunch, this time in the wheelchair as you couldn't walk anymore. You could no longer hold the fork properly and would drop your food. You had trouble getting the food to your mouth and it would end up in your ear. I started to have to feed you and help guide the fork or spoon.

About the third week after you were admitted, you started having hallucinations. And by this stage the twitching was happening 24 hours a day. Every fifteen minutes or so your arms and legs would go rigid, and you would jump, startled, when someone came into the room.

From around about this time you started having real trouble eating then swallowing your food. The dietician came in to see me to work out what food you liked and to start having it blended, along with soft food like custards and jelly. Then you started to just have Sustagen drinks.

Somewhere around this time your appointments with the physiotherapist were stopped as you were blacking out.

You had a spinal tap sometime in the week starting 13th July which caused you a lot of pain.

Also, one night mum, dad and I were downstairs at the café eating our dinner and we heard this terrible scream. I looked at them both and said, “Oh no,” and shot up the stairs to your room. There you were with nurses running in trying to hold you down, you were having a fit and screaming. It was horrible.

You now could not speak properly, only very slowly and with a drawl, and you would stop for ages then start speaking again. We asked you a couple of questions about the business, you could not remember a name and got quite distressed then started having a severe spasm.

The neurologist advised me that you would have to go into a nursing home. A doctor came from one facility to assess you and was there for over an hour. While undergoing these tests you blacked out and they had trouble reviving you. It was terrible to watch.

An RN from an assessment team came in to tell us that there were no beds at this facility so we had to look for a nursing home.

On the afternoon of Thursday 29th July a counsellor came to talk to you and we cried together. You couldn't talk. That night you had a bad night crying and yelling out and hitting your bed.

I came in late on the Friday as I had a terrible headache. Mum and Dad came in earlier to be with you to let me stay home and try to get rid of the headache but you were so upset and they couldn't calm you down. The nurse rang me at home and said I had better come in. I arrived about 2pm and remember cradling you in my arms as you cried and cried. You wanted to see your sons, Tanya and Bailey, you were so upset you hadn't seen them for a couple of days. The nurses drew the curtains and dimmed the lights and I laid on the bed with you and you finally fell asleep with your hand and arm twitching and hitting me in the face and body.

Around this time one of the nurses said they walked into your room during the night and you were lying there with your eyes wide open. This happened all the time from then on and you hardly ever blinked, just stared. When you later went into a coma at the hospice you still laid there with your eyes wide open.

On the Friday you had a “PEG” feeding tube put into your stomach. When you came back from theatre you were so calm and peaceful. I said to the nurse and the neurologist, “I wish he could have been like this before.” You were going through so much pain and trauma.

On Saturday 31st July, 1999, a meeting was arranged with the neurologist and an RN nurse. Mum and Dad came with me to discuss you. The neurologist told us the diagnosis had come back from the CJD Registry that Creutzfeldt Jakob Disease was suspected, and he tried to explain to us this terrible disease.

The head doctors came from the hospice to assess you and said that you needed more help than what a nursing home could provide. You were going into a coma and things were very serious.

On the early hours Sunday night you ripped the tube out of your stomach so on the Monday you had to have the tube put back in. On the Tuesday 3rd August, 1999 you were transferred down to the hospice.

You arrived by ambulance about 1.30 – 2pm. I was waiting for you to arrive.

The nursing staff put you in your room the palliative care doctors came to see you. They were about to shine a light in your eyes and I said, "Don't do that, he can't stand the light." They asked what happens to you and I said, "He goes like a werewolf and freaks out and will go into a fit." They said, "We need to see what happens," so you went hysterical with the light and they watched as I calmed you down the way I had been doing for weeks. This was the last time you had fits, spasms etc.

At the hospice they padded the sides of the bed to protect your arms but from the day of admittance you were sedated and had gone into a coma. You were finally peaceful. They looked after you very well.

The last thing I remember having to do before you passed away, which was very hard was one of the palliative care doctors asking me to go down to the "quiet room", and I had to sign papers to allow your body to be taken to the Adelaide University where, as I understood it at that time, your organs and parts of your body were to be sent over to the Melbourne University. After signing these forms I walked back into your room and realised what I had just done and you were still lying, breathing in your bed. I smothered my face in the pillow and cried. No one came and talked to me or counselled me, no one bothered to explain the autopsy process, I have never forgotten this. This I feel was very important and a necessary thing where someone should have sat with me, even though I knew what I had done would help the medical profession.

On Monday 16th August, 1999 you passed away at 4.30pm.

When I look back on the symptoms you started getting several months before, the stumbling and pain in your left arm and leg, I remember how we both said it was most probably arthritis because of your jobs and the hard work you did.

I hope that from this diary/letter I have written to John after he died will help someone to be able to diagnose a patient.

John, I now have a lovely man in my life, Ross. We were married on the 8th March, 2008 and I know you would be happy for me. Your boys told me on my wedding day, "Dad is looking down and he would be very proud and happy for you Mum." I never thought I would meet someone else and to be so lucky to have another special person in my life. To feel happy and loved again is wonderful and I feel very blessed to have been able to have two such lovely men in my life.

Goodbye darling,

You will always be in my heart and thoughts,

Love,

Carolyn