My brother, Bernard John McMahon

Bernard has always been an enigma. He had been examined by more psychiatrists than Woody Allen over his 65 years, but none could give a clear diagnosis of his condition. And that is because his was a unique condition, that of being Bernard.

In the quaint way that bureaucrats like to categorise, Bernard had been described as "dual diagnosis", meaning, I gather, that as well as intellectual disability, he had secondary psychiatric symptoms. If only it were that simple. Bernard's list of symptoms included autism, obsessive-compulsive disorder, echolalia, as well as a list of physical ailments partly relating to the ageing process. And his inability to focus on learning tasks for any length of time meant he could not attend normal schools.

But Bernard was far more than the sum of these parts, these inconclusive symptoms. Bernard was a beautiful man, who survived despite his surroundings and the cards he had been dealt. He was loved by virtually all who knew him, his family, the many kind people who cared for him at Peat Island Centre, and those who cared for him before that.

He was his own person, with his distinct personality intact after 53 years in an institution. He had humour, mischievousness, an almost complete absence of guile, and a very direct way of articulating his needs and wants. If he ordered fish and chips without salad, and it was delivered with salad, you could be certain he would put the salad aside.

Bernard could be enormously frustrating when asked to carry out a complex task, such as putting on his shirt when he would rather conduct an imaginary conversation. He was entirely capable of dressing himself, but often found his inner world more compelling than the need to dress for the day ahead.

He had skills which he often chose to conceal, in order to have other people do things for him. He liked to be around other people, to chat to them, and especially to feel loved by them, which was signified by their doing things for him.

He would sometimes ask me to tie his shoelaces. I would say "Bernard, you can do that." He would reply "No I can't, I don't know how to." I would say "Yes you can, now just do it".

And he would. I don't believe it was laziness, it was his way of reaching out to those close to him.

He has experienced the good, the bad and the ugly during his stay at Peat Island, though not in that sequence. Peat Island Centre today is a model of humane care compared with its not so distant past. Bernard was there when it was massively overcrowded, under-staffed and with inadequate monitoring of the care delivery. He was there when it accommodated over 600 boys, and they were mostly boys in those days. He spent some time at Milson Island when it housed the overflow. Now there are fewer than 80 men and women, mostly aged people, in the same accommodation. The average tenure of residents at the centre is 45 years.

Bernard was born in 1944, towards the end of World War II, one of twins. They were very premature, not much more than 6 months, and Bernard weighed a little over 1 kilogram. His twin brother, Neil, survived only 11 days.

Bernard's father Garry was away with the army in the Pacific. Among other things, Garry was present in the bombings of Darwin, and took part in the last allied amphibious landing in the Pacific at Balikpapan.

Bernard's postnatal care was initially in a humidicrib. Later he was transferred to at Tresillian, a specialist centre for the postnatal care of frail babies. While he was there for around 3 months, my mother lived at my grandmother's house, and had to express milk daily for Bernard.

Bernard's survival was remarkable by the medical standards of the day. Some months after his birth, an article appeared in the Sunday Telegraph about him, with a photograph of him in the arms of his mother Hope.

He developed well, and after building his strength, he was physically entirely normal. He did not speak, but it was clear that he could understand what was said to him. Although later than average in some developments, it was not evident for many years that Bernard would not be able to lead a normal life.

Bernard had a tonsillectomy at age 5, and in those days post-operative care meant isolation from his parents. Bernard found that in order to get what he wanted from these strangers in the hospital, he had to ask, so he started speaking, in sentences. Shortly after, he began school at St Joseph's Convent, Goulburn.

When I began at the same school at age 4 ½, Bernard, then 7, was in the same composite class. He was not academically inclined, and if the nuns who taught there failed to retain his attention, he would leave the class and explore the playground. On one occasion, he was brought back in to face the punishment for his absence.

The followers of the Blessed Mary McKillop believed in firm discipline, and Bernard was standing with his hand out ready for the cane. Before she could strike, Bernard withdrew his hand and said: "Sister, don't cane me, give me a kiss."

The nun was unable to continue in the face of this innocent plea, and Bernard escaped his punishment. He did not get the kiss, however.

Our family soon moved to the Central Coast, with my father's employment, and again Bernard and I were in the same composite class at Avoca Beach Public School. Bernard still found classes uninteresting, and continued to amuse himself and distract others, inside and outside the classroom. Eventually, the Headmaster, a Mr Hogg, called our parents in for an interview. He announced: "Either Bernard goes, or I go".

Bernard went.

One of Bernard's more dangerous obsessions was lighting fires. He loved watching flames and smoke, and matches had to be well hidden around our house. Given an opportunity, Bernard would be in the back yard setting alight a pile of papers or rubbish or rags. This obsession may have contributed to his subsequent, and as it turned out, even more dangerous habit, that of smoking.

Our parents tried several "special" schools: one at Kincumber, I believe also run by the Sisters of St Joseph, and for about a year at a Catholic boarding school in Melbourne. In the early 1950's, this required expensive plane trips for visits to Bernard, and for Bernard's trips home in the holidays. My mother and I spent a year living with my grandmother in Sydney, so my mother could find work and help support the extra expense of that school, and of the travel.

Bernard did develop various new skills while at that school, and could help with domestic work, making beds and washing dishes. However, eventually the brothers there advised my parents that he was beyond what they could manage at that school, and Bernard was back living at home.

It is worth remembering that at that time, people with disabilities were treated with avoidance and suspicion. I was occasionally taunted by school colleagues about my "mad brother" (their words), and this sometimes led to fights.

Such community attitudes had a profound effect on my family. My family seemed ashamed of Bernard, and his existence was revealed to as few people as possible, despite his living at home for the next 2-3 years. I in turn absorbed this attitude from my own family, from neighbours, from school colleagues and from others in the community, and I carried it with me into my early adult life. None of my friends at university and later knew that I had a brother.

The presence of a child with a disability caused major divisions within my family. There were feelings of guilt and shame, and accusations of his disability being inherited from one side of the family. In fact, Bernard's condition was clearly caused by brain damage at around the time of his very premature birth. As well, it caused a rift over religious issues, with my mother adamant that she would have no further children, at variance with Catholic dogma.

My parents concluded that it was not possible for Bernard to continue living at home indefinitely. They agreed with the prognosis of the brothers at the Melbourne school, who said that his behaviour and volatility would worsen as he moved through adolescence and into adulthood. In 1956 he was place in Peat Island Centre, at the age of 11.

Bernard was devastated at being taken from his nurturing home, and being placed in a large institution with hundreds of other boys in various physical and mental states, in overcrowded conditions. As his younger brother, who had always been very close to Bernard, I felt desperate about it, but realised my parents had no alternative. On visits home, Bernard would scream about being taken back to the Centre.

My memories of Peat Island in those early days were of misery, of naked men screaming behind cyclone fences, of an alcoholic doctor who was the resident physician there, of the many people there with severe physical and mental disabilities, and of Bernard's horror of each return there. I dreaded visiting him in his surroundings there.

My family maintained contact, visiting regularly and taking Bernard for picnics at Brooklyn, at Kangaroo Point, at Berowra. Bernard came home for holidays at Xmas and other times.

I left home at 16 to go to university, and visited less often, mainly during holidays when Bernard was home with his family.

Bernard's father Garry died in 1966, two weeks after Bernard's 22nd birthday. Garry was only 54, and died of a stroke after a long history of strokes and hypertension. He had long been on a war pension, as his illness related to what would now be called post traumatic stress disorder from his service in the Pacific war.

My mother continued visiting and having Bernard home for holidays, sometimes with friends, sometimes with me.

I lost touch with Bernard during the 1980's. I was preoccupied with my own somewhat complex family, with my academic work, with my job, and was living overseas for a time. By the end of that period, my mother had also stopped visiting. She was then around 70, no longer had the support of friends to assist, and found it too emotionally and physically demanding to continue to see Bernard on her own.

Bernard of course missed his family terribly. He often spoke to Peat Island staff about it. They contacted me, and asked if I could visit. I resumed visiting in about 1990, and committed to Bernard and to myself that I would never abandon him, that I would always be around for him.

I vividly remember that first contact, when I saw him sitting on the verandah of what was then the administration block, now Bindaree. It was the same Bernard that I had last seen years earlier, dressed neatly, waiting patiently to see his long lost brother. My own emotional response was overwhelming, Bernard just seemed very happy to see me.

Our contact had been regular ever since. He always loved visiting his mother at East Gosford on birthdays, Easter, Xmas and other occasions. He liked going to Brooklyn with me for a meal of fish and chips, or perhaps for a muffin and coffee.

Much has happened at Peat Island over the last 20 years. It was transferred from the Department of Health to the Department of Community Services in 1989, and later to the Department of Ageing Disability and Home Care, and recently has become part of the Department of Human Services.

I can't resist commenting on the irony that Bernard was introduced to smoking at the Centre when it was run by the Health Department. He quickly became an addicted heavy smoker, leading eventually to severe emphysema, and to lung cancer and to his demise last weekend.

The Disability Services Act was passed by the NSW Parliament in 1993, prescribing standards and principles for the care of people in residential care. The government congratulated itself on having passed a law which had cheaply appeased community concerns about standards of care. Belatedly, the government discovered that their own large institutions were in breach of the new act, and that the cost of accommodating their resident populations in group homes in the community would be prohibitive.

The government introduced transitional provisions to allow the large residential centres time to move to compliance with the DSA. I served on a committee in the mid-90's at Peat Island, planning the transition for that centre. This has eventually been overtaken by the planned move to new facilities next year.

One of Bernard's many remarkable features was his uncanny long term memory. He had vivid recall of minute details of his grandmother's house, which he lived in for the first 5 years of his life, and had not seen since. He could describe furniture, room layouts, and even the location of an ancient wall telephone that had been in the house since the 1920's. Recently he described to me a scene where his grandfather, who died in 1952, was pouring porridge from a saucepan on the gas stove into a bowl, and how he ate it.

My grandfather had a wall pendulum clock in a glass case. It was a Vienna Regulator, so called for its accuracy, manufactured in about 1870. It eventually went with my grandmother to the United States, where it passed to my aunt who lived there, and then returned to me in about 1996, following my aunt's death. Bernard was sitting in my living room in Mosman one day in the late 1990's, and commented that the clock used to be on the wall in his grandfather's house, above the piano. This was exactly as it had been in the 1950's.

Bernard also had a keen memory for TV shows that interested him. For many years he had been restricted to smoking only the lightest tar and nicotine cigarettes, but when he received his weekly pay, he could go to the shop near Peat Island and buy his own cigarettes. I found him a few years ago with a packet of Benson and Hedges, and said that he knew he was not supposed to smoke them. Why did you buy them, I asked.

"It's when only the best will do," he replied immediately, echoing the words of Stuart Wagstaff in an iconic cigarette commercial for B&H cigarettes in the 1960's.

Bernard loved the rock and roll music of the 1950's. Our mother liked Bill Haley and the Comets, an early rock group, and Bernard always loved their hits, such as "Rock around the Clock".

Bernard's health has deteriorated markedly in recent years. He developed osteoporosis, and broke his femur in late 2005. This went undiagnosed for a few months, and he had a hip replacement in February 2006. He had severe emphysema, despite reducing and eventually eliminating his smoking. He has had several adjustments to his psychotropic medication over the last decade.

The final blow came when a lump on his buttock was discovered on 11 October, ten days before his 65th birthday. This turned out to be a secondary tumour, arising from a primary lesion in his lung, leading to his passing away peacefully just 69 days, less than 10 weeks, later.

Bernard will be sadly missed. He brought joy to those who knew him. He was regarded by all as a wonderful man, who maintained his humour and integrity in the most difficult of lives. He was loved by the staff who cared for him for over half a century, by his family, and by friends he met only briefly.

Bernard will be remembered with love.