

SUMMARY

I wrote this Submission and then read over it again and again, thinking I should somehow shorten it.

Given that it is a history of my brother, I could find no way to do so and remain true to what it was that I was attempting to do here.

I wanted to be heard by the Committee, on humanitarian grounds.

I wanted to ensure that the human element is heard and understood in amongst your Terms of Reference and the Submissions of well-qualified, professional people who work in the field day after day.

I guess I wanted to attempt to ensure that my brother had a voice that he didn't have in his life.

And so, this summary is perhaps simply a warning that it is an 8 page long document of some of one human beings travels in a tormented world.

April 27 2005

Senate Select Committee on Mental Health
Department of the Senate
Parliament House
Canberra ACT 2600

I am not employed to work with the mentally ill and I do not profess to know the in's and out's of our mental health system.

I have no doubt that many highly regarded, academically qualified, professional people will make valuable submissions to this Committee.

I speak as my mentally ill brother's sister, having tried over many years to get help for him.

My interest is simply humanitarian.

My brother was diagnosed as suffering from schizophrenia, with related paranoia some 15 years ago at Morrisset Hospital near Newcastle although had we known more of the illness earlier perhaps we'd have recognised symptoms at a much younger age.

As I write I find myself thinking, "Good grief, can it only be 15 years ago?!"

The doctor at Morrisset said to us, "Did he initially use drugs and/or alcohol to escape the voices? Or does he hear the voices as a result of the drug and alcohol abuse? We'll never know for sure. Who knows? Only he does and he can't tell us."

It was a long road to that point of diagnosis when he was aged approximately 37 and the road only got longer and more heartbreaking.

There were juvenile detention centre stays in his mid-teens, there was heavy drug abuse upon his release, followed by a methadone program some 3 years later.

Alcohol abuse followed shortly after – excessive, heavy drinking bouts during which he was abusive and often delusional. Summary offences, minor crimes of predominantly property damage, saw him jailed a number of times for brief periods.

Alcohol was to be his nemesis for many years. He wandered the streets of Sydney, obtaining a bed at Matthew Talbott Hostel for Men in Darlinghurst at times. There are kind and caring people to be found there.

More usually he slept in the parks and streets of the inner city of Sydney, alternating those nights with visits to our parents on the north coast of NSW.

As we watched his health deteriorate, both mental and physical, we feared there was more going on than only alcoholism. Sober or drunk he was delusional, seemingly suffering dreadful hallucinations. He chattered to himself, carried on entire conversations with unseen people and often seemed totally disassociated and detached from everyone and everything around him. He spoke of hearing voices instructing him, of a constant static noise in his "head".

My parents were living in fear of this much-loved, once gentle son of theirs who'd become a stranger to them, in spite of their love and caring of him.

He'd return to their home dirty and unkempt, shaking, physically sick and muddled thinking, delusional and hallucinating, fearful of shadows and unseen evil beings. He was disdainful of their love and care and yet sought it and them out.

I spoke with general practitioners about what could be done for my brother, how I could obtain help for him. I was told that he needed to seek the help himself, that he had to "want" help, that there was nothing to be done until he determined he needed help.

I was told that unless I could provide concrete evidence of his mental instability nothing would or could be done. This evidence would need to be from someone who lived with him on an ongoing basis, who could attest to his "odd" behaviours, someone such as his own general practitioner or a mental health worker who had observed him.

"My brother is homeless. He doesn't live with anyone. He visits us and then one day he walks out the door, saying he's going to the shop, returning months later. He sleeps on the streets. He talks to people who are not there and then answers his own questions. He mutters and glares at strangers in the street and is often physically beaten up as a result of that behaviour. He drinks something in the vicinity of a 4 litre cask of wine a day and sometimes adds a bottle of scotch for good measure. A photograph taken of him steals a little piece of him. 'They' listen to his thoughts through the telephone. He fears the evil thing that lives in my car. You tell me how I am supposed to get him to see a general practitioner and I will do it!"

I spoke to the Mental Health team at the local hospital time and time again, only to be told that they couldn't understand why he hadn't presented himself there, that they'd not seen him either as an in-patient or out-patient. They told me that if I brought him to them they'd be happy to speak with him. "I don't want someone to 'speak' with him – I want someone to HELP him! Tell me how to get the evil thing out of my car so he will get in the car and I will bring him to you!"

It was in the early 90's on one of those visits to my parents that, in desperation after trying so many other avenues to obtain treatment for my brother, my family and I made one of the hardest decisions we have ever had to make.

Feeling it was our only option we made application to the Local Court for him to be committed to an institution under the Inebriates Act. He was taken to Morrisset Hospital, remaining there for some 6 months.

He was released after his diagnosis, with a prescription for anti-psychotic drugs. He went to a drug and alcohol free residential program, remaining there for some months.

He returned to the North Coast where the Department of Housing provided him with emergency housing. He was medicated and managing quite well, visiting the Hospital on occasion and involved with group counselling there.

One day he trashed his home, simply trashed it. There was not a stick of furniture left intact, the television was shattered, he had pulled the phone out of the wall, wires and all. He was huddled in the corner muttering and distraught.

'They' were back. 'They' were listening to his thoughts via the telephone. 'They' knew everything about him. The TV watched his every movement. He would no longer take his medications because he was 'better' now.

Again the Mental Health team suggested that I bring him to them. He wouldn't remain indoors for any period of time, how was I going to get him into the enclosed spaces of my car and then to the hospital?

And so he was back on the streets of Sydney, often coming to see me with bruises and gashes resulting from being bashed. Who knew why – he certainly couldn't explain it to me.

And then he was medicated again. He lived in a boarding house in the inner west, close to my home. He agreed that The Office of the Protective Commissioner would look after his financial affairs, paying his rent and providing him with an allowance.

Again, he decided that he was all 'better' and therefore no longer needed medication. He was back on the streets although he agreed to allow The Protective Office to continue management of his pension, paying him an allowance a couple of times a week. There are kind and caring people there, too. Although it's unfortunate they seem to have a high turnover of staff, which results in distress for those such as my brother when there is yet another strange person in a familiar place they must see to get extra money.

In one of his acute episodes he decided he would tell The Office of the Protective Commissioner that he wanted all his money paid to him. This amounted to a sum of approximately \$8,000 that had been saved on his behalf by the Protective Commissioner's Office. He said he had been told by 'someone' who was hanging around outside Matthew Talbott Hostel that the Protective Commissioner had no right to keep his money from him and that he should get it back. This person also told my brother that he'd "help look after it" for him.

His was a generous spirit. I worried he would be taken advantage of by someone less affected than he.

Fortunately, I had developed a good relationship with that Office over the years and had asked them to call me if there were any problems. My brother was aware of this and had given the Officer his permission to do so. His Officer called me to tell me that my brother was in the office being very abusive and demanding his money. I asked to speak with my brother and convinced him to leave the office, to let me deal with it, suggesting he come and see me at home.

His Officer was prepared to hand my brother, a homeless alcohol affected and clearly mentally unwell man, that amount of money. I understand and accept their hands were tied in the matter as his was a voluntary management of his affairs.

Further enquiries, with an appearance before The Guardianship Tribunal by us, resulted in a financial management order under Section 25H of the Guardianship Act being made.

The Office of the Protective Commissioner on this occasion is one of the very few times in all those years that any of the organisations I have approached has truly listened to me, his sister.

There was a night when my brother came to my house shortly before 11pm. He was dirty, shaking and confused and alcohol affected. He had been the victim of a bashing, leaving his face badly bruised, one eye black and almost closed, a gash on his cheekbone and another high on his forehead.

He simply said, "I am sick. I'm sore. I need help, Sharon".

I brought him in to my home, made him a sweet coffee and then encouraged him into the shower, giving him clean clothes to put on afterwards. My husband and I sat and talked with him for some time. He agreed to come with us to the Hospital, to seek help for his injuries and arrange for him to talk with one of the Mental Health Team and be admitted.

I phoned the Hospital and asked to speak with one of the Mental Health Team in the Missenden Unit about arranging for my brother to be psychiatrically assessed. He had been treated there on previous occasions.

I was advised that I would need to take him to the Accident & Emergency Ward at the Hospital for medical assessment as that was the only way to have someone admitted for psychiatric treatment outside the hours of 9am to 5pm.

I was told that once there, I should explain my brother's history to Admissions and request that the Psychiatric Registrar be called for assessment of him.

We arrived at the hospital at approximately 11.45pm and were seen at about midnight by the Triage Sister. I explained my brother's past history of mental health and treatments, telling her of my phone call to the Mental Health Team worker and his suggestion that he be called.

We were told to sit down and wait, that we'd be seen in an hour or so.

At 1am, his name was called and he asked me to go with him. I asked the Sister if the Psychiatric Registrar had been called to do a psych assessment. She informed me there was nothing about that on his file, he was there for medical treatment of facial injuries only. I pleaded for her to call Missenden Unit. With no treatment offered she told us to go back outside and wait whilst she sorted it out.

1.30am and I decided to phone the Missenden Unit again to seek their assistance. The worker there told me he would phone the Triage Sister and explain the circumstances of my brother's presentation to A&E. I returned to my brother and husband.

At 3.10am I approached the Clerical Assistant, asking why so many people who had come in after us had been treated and left, whilst my brother was still sitting waiting to be seen. She told me she didn't know, she was "just a clerical" and we'd just have to wait. I insisted on speaking with someone in charge. She told me to sit and wait.

By this time, I was working hard trying to convince my brother to stay. He was getting more and more agitated and wanted to leave, saying that this place was no different to any others in their treatment of him.

At 3.20am the Triage Sister approached us, asking what our problem was.

I told her how long we had been waiting with no treatment for my brother. I told her of his need and desire to be psychiatrically assessed. She responded by inviting us into her office where she would "explain the delay".

A second Sister joined us in the office where heated words were exchanged, with neither of the two Sisters able to tell us when my brother might finally be treated, let alone psychiatrically assessed.

I said I would take my brother home with me, forget it all and simply write it off as yet another sad story of the treatment of the mentally ill in our society.

The Sister immediately said there was a bed available for him to lie down in while waiting for treatment to be available. When asked when that would happen, she said she really didn't know.

I asked about admission to the Missenden Unit.

She told me he'd need to be psych assessed first.

"So arrange for that to happen. I told them at Admissions that he required psych assessment" I said.

"He has presented here for physical medical treatment. There's nothing on his file about psych assessment being requested" she said.

Round and round and round we go.

My brother agreed to wait and after settling him in a bed, my husband and I left the hospital to go home for some rest, reassuring him that we would be back in the morning.

We had waited 4 hours and still my brother had not received any treatment for his physical injuries, let alone any discussion of psych assessment.

I phoned the hospital at 11am, to be told by a Doctor there that my brother had not been seen for about "oh, 2 hours" and they didn't know where he was.

I asked her if he had been treated or psych assessed. She responded by again telling me that she didn't know where he was, that he had left the hospital and what psych assessment was I speaking of.

Again I asked if he had been treated for his facial injuries. Again she responded by telling me that he had left the hospital some 2 hours previous.

Round and round and round we go.

I told the doctor that the reasons for us seeking help for my brother in the first place (schizophrenia with associated delusions and not being medicated), asking if he had been seen by the Psychiatric Registrar. She told me there was a "notation" on his file of his schizophrenia but no mention of the request of a psychiatric assessment. She would not, or could not, tell me if the Psychiatric Registrar had even seen him.

When I asked her what we should do now, she told me that the Hospital could notify the Police and request that they keep an eye out for him. I asked that she do that and left my contact details with her to be forwarded to the Police.

I contacted the local Police, who told me that given the history I had provided about my brother, she would arrange for his details to be broadcast to all Stations.

This situation with the Police was the second occasion I had been truly listened to in my quest for treatment of my brother.

I phoned the Matthew Talbot Hostel thinking he may have gone there. They told me that they had had a phone call from the Hospital at 7.30am, requesting that a bed be held for my brother. This raises the question – was he psych assessed or was he, in fact, ever going to BE assessed? At 7.30am the Hospital was making arrangements with the Hostel for a bed to be available following his discharge. Seems to me there was no intention for him to be either assessed or admitted to Missenden Unit.

For the next 2 days, my husband and I scoured the city in all his usual haunts looking for my brother in the hope of being able to convince him to return to the Hospital for medical treatment of his injuries and psych assessment and to reassure ourselves that he was all right. We had no luck locating him.

Around 2pm that same day, the same Doctor from the Hospital phoned me to tell me that when I next saw my brother I should tell him that an appointment had been made for him to see a plastic surgeon on the following Thursday. She said an x-ray showed facial fractures and spoke of her concerns of bone fragments.

“My brother is homeless, schizophrenic, an alcoholic who has been heavily drinking for some months, is not taking his anti-psych medications, was harshly assaulted some nights ago and has a previous admission history to your Hospital. Do you really think my brother who, like so many others in his situation, drops out of sight and has no contact with his family for months on end drops in at my home every second day for a coffee and a chat?? Do you REALLY think he is, given his treatment at your hands last night, going to pop in and present himself for ANOTHER bout with your system?!?”

My brother turned up on my doorstep about 10 days later. He refused to return to that Hospital or any other. His facial fractures were untreated and he was not psych assessed.

I had not formally complained of other such incidents in the past with that and other hospitals, but that whole sorry incident was the subject of written complaints to the management of the Hospital, the Premier, the Health Minister and anyone else I could think of.

Another late evening I received a call from inner city Police, telling me that they had my brother in custody and were unsure of how to approach him. They told me he was “like a wild man”, that it had taken a number of Police to subdue him to get him into the Police van.

Arriving at the Police station, my husband and I found 5 Police officers standing around looking in amazement at my brother who was confined in an enclosed dock area. He was again dirty, wild-eyed, kicking out at his surroundings, threatening any who approached him, face distorted and yelling incomprehensibly.

I approached him in the dock trying to make eye contact with him, trying to have him recognise me, talking to him, trying to have him hear me over his yelling.

Generally my husband and I have been able to calm my brother sufficiently to have him hear us and this time was no different. We talked with him for a time, finding him distressed and confused, talking of the evil being he had pushed away from him on the railway station. That evil being was, in reality, some poor man on his way home from work. He was standing on the platform reading his newspaper when my brother pushed him in the back, sending him on to the tracks.

With the Police, we accompanied my somewhat calmer but still confused brother to the back of a Police van to be taken to another station with overnight lockup facilities. He appeared in Court the next day, was adjourned to another date and was taken to Long Bay.

At his next Court appearance, I begged the Public Solicitor and Court to have him psych assessed. I was told it had nothing to do with me, that I had no place in the process, he was an adult and his privacy and rights were to be observed at all costs.

My brother was found guilty and sentenced to the rising of the Court. He was back on the streets again – un-medicated, drinking heavily, perhaps psychotic, certainly hallucinatory and delusional, in the middle of an acute episode suffering a deity delusion.

These are just a few of many incidents over many years, all examples of how I believe this system of ours lets down those in need.

In more lucid moments my brother spoke of ‘noises’ in his head, voices telling him to do things, frightening images he saw daily and when he least expected it, the certain knowledge that ‘they’ were listening and watching.

He once described it thus: “Remember the old radio on the mantle piece and how you had to have it on the station perfectly, or it was crackly with loud static? I can almost hear it but not quite, like a whisper. All the time, it never goes away. If I just listen more closely, I’ll be able to hear what they are saying?”

My brother led a tortured existence for many years. We, his family, wished only for a place of peace for him.

My brother has had his family trying to help him, to find that one person or thing that could assist him with finding some peace, some quiet.

What of those like him who have no family to care? What of those like him who have none to fight for dignified, caring and appropriate treatment for them? What happens to them?

When our system chooses to not listen to, to not hear, those who have lived with one such as my brother, they do us all a huge disservice at a huge cost to us collectively as a society.

When our system chooses to devalue, ignore and disregard the valuable, intimate knowledge and understanding one family member has of another family member, there is a large price to pay for all concerned.

Whilst I accept that there are those people who would wish to medicate and institutionalise others, claiming mental illness, for questionable benefit to the person concerned, do not paint us all with the one brush.

There needs to be a place within the system, ensuring families of the mentally ill have a voice and will be heard in their pleas for help for their loved one.

We need to ensure that a family member presenting with a loved one at midnight at one of our Hospitals, is not told that getting someone admitted for psychiatric treatment outside the hours of 9am to 5pm is nigh on impossible.

Apparently acute episodes of schizophrenia occur at the most “inconvenient” times for our system. It needs to be told that an acute schizophrenic episode is rarely “convenient” for the sufferer, never mind the system.

I have no doubt that many of the frontline mental health workers are kind and caring people, hamstrung by lack of funding, weary from the struggle to provide adequate services on a shoestring budget.

I don't have any earth shattering, one-size-fits-all recommendations to address the Terms of Reference of this Senate Committee. No doubt those professional people I spoke of earlier who work within the system have many wonderful thoughts on solutions.

I only know that my society was unable to provide a useful and ongoing solution for my brother.

I don't have the answers for this problem. If I did, I'd have been able to ensure my brother received the treatment and assistance he deserved.

I wanted to speak for my brother and others like he and I, to ensure that the human element in your Senate Committee is not overlooked. I have done so.

Thank you for this opportunity to speak of the frustration of years of seeking assistance.

At approximately 11.30pm on October 6, 2003 Anthony John Wood was sleeping in Regimental Square near Martin Place in Sydney where he had slept for a number of years.

He was wrapped in a blanket, his head resting on his knapsack, sleeping soundly – just another homeless man in this city we live in.

He was murdered as he slept.

That man was my brother, Tony.

The man who murdered my brother has claimed a mental illness.

Not the way I would have wanted, but my big brother Tony has some peace finally.