

ATTACHMENT TO MY SUBMISSION NO 367

I wish this attachment to be part of my submission as I feel the incident I am about to report strengthens my belief that there is a vital need for long stay accommodation for many people who are not able to care for themselves. They add unnecessary strain on already under-resourced and under-staffed hospitals, escalating costs needlessly. I would also wish to stress the need for a review of the Privacy Act, which at times is frustrating beyond description. Many aspects of this Act are totally outdated and only add to the despair and stress on families and carers. In this light, maybe there is a need to "box" the Act as it applies to mental illness patients - not sure.

My daughter presents herself at various Emergency Departments in Sydney, sometimes several times a week. She is sometimes admitted, after sitting in Emergency for anything up to 20 hours, other times she is discharged. Many, many times going back just a few years, discharged, knowing full well that she was psychotic, had no money, no keys to her home, and at time barefoot and no warm clothing.

On 23 June 2005, I got a call from my daughter to say she was at the Emergency and feeling very unwell. As I was not at work, I immediately went to see her and was told by the staff that there are no beds but they are trying to get her admitted at a private clinic - would I be ok to take her home with me. I duly did, as she had been given a valium and was settled. They suggested I bring her back the next morning so she could then be transferred to a private clinic. I duly took her in at 9 and sat with her until lunchtime and was again advised to take her home with me and they would contact me when a bed in a clinic was available. I then decided to take action myself (in the hope of speeding the process up and freeing staff from this chore) and finally managed to get her admitted and her information was duly forwarded to the clinic (I later found this to be inadequate in that medication and her C.T.O. was omitted).

Within a day of her admittance I noticed a total change in her in that she seemed quite relaxed and happy. I feel sure it is because of having company and care and the nurturing surrounds of the clinic. However, last night she was allowed out and came to my home for dinner and was anxious to get back to the clinic by 9. She was dropped back at the clinic at 9. Some time after 11 we got a call from the clinic to say that she had gone out to have a smoke and had not returned. By 1am she had not returned and apparently the Police had been advised and nothing further was done. My husband took to driving around the area and stopping in a pubs and coffee shops and generally driving up and down to see if he could see her. Needless to say neither of us had any sleep. We called the clinic this morning and she had still not been found.

My husband decided to call Emergency departments and see if she was perhaps there (maybe she had been knocked down or attacked or been harmed). I had already decided that she had been attacked and was probably dead! Well, yes she was found in the Emergency. My husband asked whether they knew she was a patient of a private clinic and they said they knew. Then he asked why they didn't contact the clinic to tell them she was in Emergency and the response was

"privacy act"!! It seems to be that people hide behind this act, because I cannot for one moment believe that it is not their responsibility to contact the clinic, firstly to inform them that she was in Emergency, and to perhaps ascertain information about her condition and medication. Apparently the clinic had also notified the police. Surely the first line of action would be to contact the various Emergency Departments in the area to firstly ascertain that there was she hadn't been raped or attacked or even knocked down by a car. Everyone seems to be passing the buck.

Now having spent a sleepless night worrying, and without our intervention, my daughter would probably still be in Emergency!

I have encountered so many instances where I am informed that because of the Privacy Act they can't tell me!! I don't want to know what she says nor does, all I want to know is if she is safe and where she will be sent. I have had instances where she has been in Emergency and there are no beds; have requested that they don't discharge her, because I will pick her up. I get to the hospital and she has been discharged!!! Stress again Where to start looking for her!

The importance of Mental Health Centres, and their most wonderful staff I cannot stress enough. At this point, while my daughter was in Emergency, the Clinic was not happy to have her back as they said she had discharged herself. Certainly not the story when they called in the middle of the night to say she had gone out for a smoke and never came back. I asked whether she signed a discharge, and of course they said no so I said she is then a patient in your care who happened to abscond, not an unusual occurrence. They then said they were unable to ascertain permission from the Psychiatrist of the Clinic which I fail to understand. Surely he would have a locum or an emergency contact number. I then contacted the Cremorne Team, explained my situation, and they took over, putting on pressure, I believe to both the Emergency Department and the Clinic, to take my daughter back. So, after all the phone calls backwards and forwards, they efficiently took over and solved the problem. I am forevermore grateful to them, as they have always been there for us in the past.

My husband and I are tired and worn out and her illness has taken its toll on us. She needs to be in long-stay accommodation. Will that ever happen I wonder? We are getting old and our fear is - who will care for her when we are gone, because without us, she would most certainly either be dead or on the streets.

The reason for the addition to my submission is:

WE NEED LONG STAY ACCOMMODATION FOR THOSE THAT ARE NOT ABLE TO ADEQUATELY CARE FOR THEMSELVES AND PUT A TREMENDOUS STRAIN ON AN ALREADY STRUGGLING SYSTEM. ALSO, IT IS PARENTS AND/OR CARERS THAT ARE SHOULDERING THIS ENORMOUS BURDEN.

THERE HAS BEEN A DEBATE FOR 15 MONTHS OR LONGER ABOUT CLOSING DOWN CREMORNE AND CHATSWOOD MENTAL HEALTH CENTRES - THIS IS A TOTAL TRAVESTY OF JUSTICE. MONEY IS SAVED HAVING THESE CENTRES, STAFFED BY THE MOST COMMITTED TEAM, WITHOUT WHOM I AM CERTAINLY NOT SURE WHERE MY DAUGHTER AND MY HUSBAND AND SELF WOULD HAVE COPEd. MANY INSTANCES ADMISSIONS WERE AVOIDED BY THEIR AMAZING EMPATHETIC INTERVENTION. PLEASE DON'T CLOSE THEM DOWN!

THE PRIVACY ACT IS OUTDATED AND NEEDS TO BE DEFINED IN CLEARER TERMS TO BENEFIT THE CONSUMER AND FAMILY AND CARER - IT IS NOT INFORMATION ABOUT WHAT THE PATIENT SAYS, IT IS ABOUT THEIR SAFETY AND THEIR WHEREABOUTS AND WHERE THEY ARE AND WILL BE SENT. AGAIN, LESSENING THE NEEDLESS STRESS AND ANXIETY WE FACE!

AGAIN, WITH A DATA BASE, MORE ACCURATE INFORMATION CAN BE GIVEN TO THE RELEVANT PARTIES, AS TO LATEST BRIEF HISTORY AND MEDICATION - (in this latest incident, the Clinic was not informed my daughter was on a C.T.O. and what medication she was on). I DO REALISE THE NEED FOR PARTICULARS NOT TO BE RELEASED EASILY, BUT THERE ARE CLEAR INSTANCES WHEN THIS NEEDS TO BE DONE FOR THE BENEFIT OF ALL PARTIES. THIS NEEDS TO BE AVAILABLE INTER-STATE.

LASTLY, WITHOUT OUR INTERVENTION - WHERE WOULD SHE BE NOW? MORE OFTEN THAN NOT, IN THE 11 YEARS OF MY DAUGHTER'S ILLNESS, HAD IT NOT BEEN FOR OUR INTERVENTION, SHE WOULD NOT BE HERE! HERE I WOULD ADD HOW IMPORTANT IT IS FOR MEDICAL STAFF TO LISTEN TO OUR INPUT (THEY CAN SURELY DISTINGUISH BETWEEN HYSTERICAL PARENTS, PUSHY PARENTS, AND NOSEY PARENTS). WHO KNOWS THE PATIENT BETTER THAN US!?

I THANK YOU MOST SINCERELY FOR ALLOWING ME TO ADD THIS TO MY SUBMISSION AT SUCH A LATE DATE. I AM HERE TO DO ALL THAT IS IN MY POWER TO FIGHT FOR BETTER OUTCOMES FOR THE MOST DISADVANTAGED MEMBERS OF OUR SOCIETY - THE MENTALLY ILL. I DO THIS WITH UTMOST CARING, RESPECT, DEEPEST HOPE, AND ALL MY PRAYERS, AND WILL CONTINUE UNTIL THIS IS ACHIEVED.