

Due to difficulties with separating our experiences and placing these and our thoughts into categories (as outlined on the RC website) we thought it easiest to just tell our story. This story may seem to be insignificant by comparison with the long-term trauma suffered by so many.

However- my daughter and I felt impelled to tell it on behalf of all "older people" – especially if the following applies:

- you are over 64
- have a mental health problem
- don't have private health cover.
- don't have a good GP
- don't have an advocate who cares

You are particularly at risk if you have a crisis on a weekend, on a public holiday or during holiday seasons.

#### **Our story begins in 2013**

In reality we now realise that behaviours we were witnessing some 33 years ago were where it really all began. The behaviours experienced back then were:

- regular panic attacks (often hospitalised) after experiencing a heart attack in 1987 (age 43)
- increased spending (when couldn't afford it)
- communication withdrawal
- etc

It took from that point in 1987 to 2013 before a diagnosis of bi-polar was given. We sometimes wonder though, if this diagnosis was a reactive one given in a crisis situation. It came after an acute episode that saw my husband in an highly dysfunctional state (inability to make decisions, work, care for himself (hygiene / food), hold a conversation (spoke in a mumbled manner) for a period of 2-3 weeks) and highlighted for us the difficulties in resourcing and obtaining appropriate and adequate critical care and ongoing support for someone over the age of 65. It's important to note here that my husband was 71 at the time of this first critical episode and still running his own business, working full time and often driving and staying interstate to work in his specialised field. As he was still a full time working member of society he had never accessed Centrelink payments (pension payments of any kind). In addition to working full time he was constantly and actively supporting his family in any way he could (2 daughters and 5 grandchildren).

It is also important to note that my husband and I have been legally separated since 1999 but had remained friends.

Major points of concern during our 2013 experience were:

- It was a weekend when we were trying to get help. The worst of the crisis happened on a Saturday night.
- We (my daughter and I) initially contacted [REDACTED] and [REDACTED] for guidance on how / where to go for critical, practical help but both these organisations were unable or reluctant to help us unless he was at risk of suicide or a threat to others. Therefore our experience with these organisations was less than helpful.
- We were advised by these organisations to contact [REDACTED] Health as this was the region of his residential address. However [REDACTED] Health said they could not help as he was physically (during this episode) staying at my home in the [REDACTED] Health region. He was staying with

me because he was unable to look after himself. [REDACTED] Health suggested that I ring [REDACTED] Health. When I did this [REDACTED] Health's response was that I should contact [REDACTED] Health as his residential address was in the [REDACTED] Health zone. I at this point broke down on the phone and said "What am I supposed to do?" No-one wanted to take responsibility for providing support.

- We were then given the details of other organisations (local crisis centres) to contact, who (if they answered at all) gave us the phone numbers of psychiatric specialists and centres such as The [REDACTED] Centre. These calls could not be made until the Monday morning. This proved useless as there was a waiting time of months before an appointment was available and we needed urgent assistance. We also discovered that some psychiatrists do not take patients over 60 years of age!

Services and assistance were seemingly unavailable to us.

It was initially suggested by friends who knew I was desperate for help that perhaps we should lie about him being suicidal in order to get an ambulance or a CAT team to attend. However a health professional friend warned us against doing this as they explained police would attend. This would have been utterly inappropriate in this instance and certainly would have exacerbated his anxiety.

In desperation on the Sunday morning I took him to see my GP (without an appointment). She immediately assessed the situation very accurately. She attempted to find a bed in hospital for him. However a bed was unable to be found in any sector – private or public. We now suspect that this may have been due to his age! For example, [REDACTED] Health Mental Health Services - Triage and Emergency Response - only caters for people between the ages of 16 – 64! I believe similar restrictions apply at Austin Hospital (Northern Health).

He was put on a "bed broker" list! In the meantime the GP sent us to the [REDACTED] Emergency Department (Sunday morning). Here the triage nurse immediately recognised the need for a CAT team (at this time the [REDACTED] Mental Health Unit ([REDACTED]) was not yet open) and contacted [REDACTED] Hospital ([REDACTED] Health) and insisted that a CAT team attend at my home that day. The assistance received through Epworth was soul saving.

A CAT from [REDACTED] did attend early on the Sunday evening. It was at this point that I realised that **age** really was the treatment decision trigger- not **depression**.

They said he would need to be assessed but because of his age they referred him to [REDACTED] Extended Care (Aged Care Facility). We attended two days later and when he was assessed it was recommended he be admitted to the Aged Care Facility for assessment, which, in my view, was completely inappropriate for his situation. I chose to take him home.

Back to the GP we went. He was referred to a private specialist who was prepared to see him. He diagnosed bi-polar disorder.

In the end we were headed in the right direction to get the help needed to move forward but the journey during this crisis was demoralising, exhausting, messy, at times very patronising and at its worst, insulting. During this period I believe he was being treated as a dementia patient by all but the GP and the triage nurse at [REDACTED] and this was so far from the reality.

### Brief summary of life during the time between episodes

He returned to living in his own house. Medication continued, family was around when things got difficult (as they often did). He continued working, there were times where we as the family felt we were on 'high alert' – times when we couldn't reach him, he wouldn't answer his phone, wouldn't return calls and we'd have to go to his house or factory to see if he was ok.

### Now to 2018.

Mid 2018 I began to see a noticeable decline in his overall mood and demeanour and mentioned this to my daughters. Our paths had continued to cross at social events (shared friendships) and many family events. During this time he was still living by himself. He continued to work long hours and travel long distances for work. He was now 74.

By the end of November it was evident that he wasn't coping with life. He was having difficulty attending family or social events or would find he was unable to get out of the car when he arrived.

On the 9<sup>th</sup> of December 2018 he asked me if he could stay at my place as he was feeling extremely anxious and agitated and acutely aware that he didn't want to be alone. This agitation escalated. I rang my daughter feeling quite distraught, not knowing what to do or where to go for emergency help after our previous experience. It was again a weekend.

My daughter rang [REDACTED] on the Saturday and finally spoke to someone who advised that we could get a referral from [REDACTED] Hospital for admission to the [REDACTED] Mental Health Unit. So with this in mind and the fact that he was still residing in the [REDACTED] Health Region (being aware of the importance of this given our previous experience of geographical complications) we thought this would be our best option.

In the early hours of Sunday morning (11<sup>th</sup> Dec) he woke and asked me to take him to hospital. We arrived at [REDACTED] Hospital about 6am. He was triaged immediately and was asked if he had private health cover, which he does. Very quickly he was admitted upstairs for assessment, which was very thorough. He was given a full range of physical tests and a psychiatrist attended. She gave him a full assessment with me present. At the conclusion of this she pulled me aside and said to me that she was going to recommend admission but she said that they couldn't admit him into [REDACTED]. I assumed this was because there was no bed available (I should have known better). I was not told that they don't admit mental health patients over the age of 64 at [REDACTED] Health Unit! She then said that she would be admitting him to [REDACTED] Centre. She told me she had never been there herself but understood it was a very good facility. She also said that he could be sent by ambulance or I could take him. I was happy to take him as I believed that this was a **general/all adult age** Mental Health Assessment Unit for [REDACTED] Region.

We arrived at [REDACTED] Centre late Sunday morning. I could find no one around anywhere to assist or guide us. In order to find someone I had to leave my husband sitting in a corridor, highly agitated. I found a door that had "Mental Health Assessment Unit" above it but it was locked and no one responded to my knocking. Eventually I found a reluctant woman (not a nurse) who took us through. I can only say that this place is chilling. The minute we walked through the doors we both realised this was not an appropriate place at all as it seems to have become (by default) a residential dementia unit. My husband **does not** have dementia. We realise now that this is the public "system", it commits anyone over the age of 64 with mental health problems into the aged care domain which in turn means that this person ends up in a Nursing Home environment with dementia patients. I did not know and was not told at Box Hill that it was an aged care facility.



Unfortunately the trauma of walking into this depressing environment exacerbated his agitation and triggered anxiety in myself. I can't stress enough how depressing this place is.

After expressing my concerns about the inappropriateness of this facility to the head nurse, he suggested I take my husband home for the afternoon and bring him back to spend the night there so that he would be at the Centre when the Psychiatrist arrived in the morning. He seemed very sympathetic and understanding. At that point I asked if I could see where he would be sleeping as I was now aware that the patients here were predominately serious dementia patients. After seeing the room and witnessing the environment as a whole, the decision was very easy to make. I discharged him and took him back to my place. To their credit someone from [REDACTED] Centre did contact me the next morning to provide me with a list of private facilities that could possibly help. I was grateful for that.

From this point on our experience improved. I took him to see my GP on the Monday who found him a bed (the next day) at the [REDACTED] Mental Health Unit where he was admitted for almost 4 weeks. He received the care he needed and is still being treated here as an outpatient.

I, as the carer/support person felt deeply shaken and frankly horrified by the ageist labelling that took place at every step of these journeys. The "box" into which my husband was allocated was a result of a system that categorises people's problems as "age assessed" (automatically) rather than specifically "illness assessed". In our experience this occurred in the public health system. During each major episode it was the private system that treated him as a patient with a mental illness- not as an old man!

**Recommendation:**

1. In the public health sector Mental Health Assessment and treatment be absolutely determined by a person's medical diagnosis and not be automatically categorised by age.