

## Submission to Royal Commission

My name is [REDACTED]. I prefer to be called [REDACTED]. I have had involvement with the mental health system on and off since 1992. I have had a number periods where I did not need to be involved with mental health services as I was managing fine. For a number of years I worked as a vet nurse. I was employed as a consumer consultant at [REDACTED] for three years from 1999-2002. In 2015 I moved to [REDACTED] for work. I had a number of admissions in [REDACTED] and one in [REDACTED].

This submission covers a number of issues from my experience in navigating the mental health system in rural Victoria.

I am going to cover the following issues:

- Use of restraint
- Feedback and complaints
- Use of police in mental health care
- Trauma informed treatment
- Patient centred care
- Cross-border services
- Co-ordination of support

### My recommendations

I would like to make the following suggestions about what is needed to improve the mental health system:

- Cultural change is the single most important need in the mental health system particularly in rural areas where the attitude of staff members does not reflect basic respect for people or current best practice
- There should be a mechanism for ensuring that a consumer is offered specialist services (eg eating disorder services) where available (even consultation-only if distance is an issue) and that any request for specialist input is followed up on
- Consumer feedback should be encouraged and actually used to make improvements.
- Cross-border services operating under different pieces of legislation should be eliminated.
- Consumers and carers should have a much greater role in mental health services including in leadership positions.
- Consumers and carers (*not* representatives such as consumer/carers consultants) should be involved in staff performance reviews, since we are in the best position to judge their impact on us/level of success/attitude.
- There should be better co-ordination of the supports people need.

### My experience of restraint at [REDACTED] Hospital

On the morning of Sunday 1<sup>st</sup> May 2016 at approximately 0800 the nurse assigned to me, B [REDACTED], realised that my NG tube had been removed, and she asked me when it had happened. I said I had pulled it out late the previous night after I had gone to bed. B [REDACTED] asked me why and I answered that it had been freaking me out because it was making me fat. B [REDACTED] said "You're lying, you pulled it out this morning because you want to play power games".

B [REDACTED] got whom I believe was the charge nurse for that shift, R [REDACTED], to come in to reinsert the tube. I knew perfectly well that the tube needed to be reinserted and had no intention of arguing this fact. R [REDACTED] had a wide bore NG tube and I told her that I needed a small tube, since I've had

surgery on my nose to repair damage caused by NG tubes in the past. I also told her that she can only use my left nostril because due to this damage, tubes will not pass easily through my right nostril. R [REDACTED] said that the tubes don't come any smaller and I told her that the one I'd just pulled out was an 8 French. She said the hospital didn't have those tubes, however on my insistence that they do she went away and returned with an 8 French tube.

My previous tube insertion in the CCU on the Friday was done very quickly and with no problems, however R [REDACTED] was being very brutal and ramming the tube hard in the hope that it would pass, causing significant pain. I told R [REDACTED] that it was not necessary to ram it with force; she just needed to feed it in gently and if she was doing it properly it would be done in under ten seconds. I said that I am a critical care veterinary nurse and I frequently place NG tubes in small dogs and cats, and that technique is more important than force. She ignored me and continued ramming the tube. It began coiling in the back of my throat and I told her this and asked her to pull back and start again. I started choking and my instinctive reaction was to pull the tube out myself, which is what I believe anyone would do if they were choking on something.

I asked for someone else to put the tube down if R [REDACTED] could not do it properly and without dragging the process out; I just wanted to get the procedure over with. At this point R [REDACTED] got extremely angry and verbally abusive and fetched restraints and tied my wrists to the sides of the bed. I continued to tell her that it was not necessary to restrain me; I just wanted someone else to put the tube down. She refused to listen to me and B [REDACTED] just stood there and told me it served me right for pulling out the tube.

R [REDACTED] continued ramming the tube as before and again it coiled in the back of my throat. I told her this multiple times but she continued feeding in the tube until it was up to the "correct" point and she taped it in place. I continued choking and trying to ask her to pull back and re-feed it, but she either ignored me, told me to shut up, or told me I was lying and that the tube was correctly placed.

By this time I was incredibly distressed and unable to fend for myself. I had tears, nasal discharge and saliva pouring all over me because I could not swallow properly. The pain in my nose and throat was excruciating and I kept begging R [REDACTED] to just reposition the tape a little if she would not replace the tube, in the hope that changing the angle a little would make it more comfortable.

R [REDACTED] and B [REDACTED] left me in that position for over 2.5 hours (from 0815 until almost 1100). During this time the medicine team came in for rounds and stood talking at the foot of my bed, ignoring me as I choked. R [REDACTED] started closing the blinds to the room and I said I wanted them left open so that people would see what she was doing, but she ignored me. We had to wait for the portable X-ray machine to arrive to confirm placement and they had to return for a second X-ray because the first one did not work.

After almost two hours of restraint, with my legs tucked under me to my right, I moved my left leg onto the bed because it had cramped. R [REDACTED] ordered me to put my leg down again. I said I was just trying to get rid of a cramp and she told me I was lying and trying to pull out the tube with my knee. She then began to restrain my leg with another strap, so I returned it to its original position.

I then tried to alter the angle of the tube by moving my head, trying to find a more comfortable position. R [REDACTED] grabbed my hair and shoved my head back again, still accusing me of trying to remove the tube. This entire time I was still choking and begging for someone else to replace the tube. By this stage I was drenched in saliva and nasal secretions. R [REDACTED] told me to stop because I was perfectly capable of swallowing. She then threatened to sedate me if I didn't keep quiet. I told her that wasn't necessary. Multiple times I said that all she needed to do to solve the problem was

to remove the tube and start again. I asked her why she was so determined to escalate things instead of behaving in a humane manner, and that her behaviour had turned a simple situation into something much worse. I told her that if I treated one of my animal patients the way she was treating me, I'd be struck off the nursing register and prosecuted for animal cruelty.

At this point I had a very sharp pain in my chest and I thought I was having a heart attack. I was able to push against my ribcage with my fist, which seemed to help a little. R [REDACTED] accused me again of trying to pull out the tube. When I explained what I was doing, she yanked on my restraints tighter so that I could not move my wrists from the bed at all. She told me again if I did not calm down she would sedate me. I said it was impossible for me to calm down in the position I was in, and if she wanted me to calm down she should address the actual problem of the tube coiled in my throat. She then sedated me with what I believe was [REDACTED].

Word came from radiology that the tube was in fact coiled in my throat, and I immediately asked for it to be removed, but R [REDACTED] said no. She was very angry at the news and told me I'd coiled it in my throat on purpose. R [REDACTED] waited another 30 minutes after hearing that the tube was incorrectly placed before she removed it. When I kept asking her why she wouldn't take it out, she said "You're not the only patient in this hospital, you'll have to wait your turn". Meanwhile, B [REDACTED] stood there doing nothing and telling me that it served me right for removing the previous tube. I asked why B [REDACTED] couldn't remove the tube, or why I couldn't remove it and replace it myself if she didn't know how to do it properly. She refused to answer me.

The tube was eventually replaced by R [REDACTED], in spite of my multiple requests for someone else to do it. When the coiled tube was removed, I asked if I could have a couple of minutes to catch my breath and recover, but she ignored me and immediately began ramming the same tube back down with as much force as she had previously. With her other hand she grabbed my hair and forced my head forward so I could not move it when the tube rammed my nose. Eventually, it went down correctly by accident rather than by any skill.

Once X-ray confirmed correct placement of the tube, I asked for the restraints to be removed but R [REDACTED] said it served me right for misbehaving. R [REDACTED] only removed the restraints when I told her my mother was about to arrive, and I asked to go to the toilet (which was supervised). R [REDACTED] said that my punishment for pulling out the tube was I had to use a commode in my room. When I had used it, she refused to remove it from the room.

By this stage I was extremely drowsy from the sedation and I slept for several hours, while my mother remained in the room. She tells me that when she first arrived, she asked why a dirty commode was in my room and why I was not allowed to use the toilet. B [REDACTED] told her that I was very pleased with myself playing my power games that morning and that the commode was punishment for bad behaviour and she was too busy to remove it from the room.

This admission was extremely traumatic, leaving me with severe food phobias which had not been present at all in the previous 20+ years of my eating disorder. After this admission, I could not be near people with food or drink and I did not sleep at night because I believed people from the hospital would grab me while I was asleep.

I have since seen a copy of my file that was obtained through freedom of information. There is no accurate record of what happened to me. The nurse did not even write that the x-ray confirmed the NG tube was misplaced although the hospital later confirmed to AHPRA that this was what had happened. Because it wasn't in my record, psychiatrists and case workers often told me (or others) that my recollection of events was not consistent with the medical records.

## Feedback and complaints

Not long after this admission my mother and I made complaints to the hospital and the mental health service. While the person we met with initially sympathetic, she said there was no evidence that any of what I said took place. It felt like the whole service then just shut down and refused to acknowledge what had happened.

I made a complaint to the Health Complaints Commission about the incident of being choked and shackled (it was not the Mental Health Complaints Commission as it didn't happen in a mental health service). I also made a complaint to [REDACTED] about the two nurses involved. The HCC could not look at anything involving the conduct of those nurses because it was with [REDACTED]. [REDACTED] still have not finalised the matter after 3 years.

My mother also tried to raise issues but she found that very distressing. The HCC never even actually responded to her complaint.

If the health service had sat down with me early on and acknowledged how distressing this incident had been and apologised for how badly I had been treated, I think things might have been different.

## Role of police in mental health care

Police should not be used to bring people in for assessment especially people who are not in any way dangerous. It is frightening and embarrassing to have the police banging on your door and putting you in the police van.

In early 2016 I attended the [REDACTED] ED fairly late in the evening with a self-inflicted arm laceration and an ulcerated mouth. I had previously called the GP and been told there were no appointments free and was told to go to ED. It took some time to be seen to and I eventually decided to leave because they were clearly busy and it was now quite late at night. I left a note on the bed stating that I'd go to my GP in the morning to have my arm attended to. I went home and put a sterile dressing and bandage on my arm and went to bed.

At approximately 0200 I was awoken by the [REDACTED] police, who were banging loudly on my front door and side windows. They stated that they'd been sent by the hospital to check on me. I told them that I'd dressed my arm myself and would have it looked at in the morning. I showed them my bandaged arm and they were happy with this and left.

At around 0415 I was awoken again by the police, who said that I'd been placed on an Assessment Order by [REDACTED] ED and that they needed to take me back in. They said that they didn't believe I needed to go because I was clearly fine, but that they had no choice. I said that I had to be at work at 0800 and they said if I hurried we could get there and back in time for me to go to work. Because there was no ambulance available, I had to be transported in the back of the paddy-van. I was body-searched and put into the van in full view of any neighbours who were awoken by the banging on my doors and windows and the police yelling at me to wake up.

Police came to my home in a similar fashion 8 or 9 times while I was with [REDACTED] Mental Health Service (2 years). I had zero police involvement before or since that time.

## Trauma informed care

I believe that mental health services need to get much better at caring for people with a history of trauma. Both in hospital and in the community mental health service there was a refusal to acknowledge that my history of trauma (including the traumatic hospital experience) impacted upon

me. One example of this was when I attended the first DBT group in [REDACTED]. I only remember the first few minutes of this group because also there was someone there helping to run the group from my medical admission, who badly spooked me. I later found out that this was a case manager from the admission, but at the time I did not match her face to her name and did not know she would be there. This set off memories of being tied up and choked by the NG tube in the CCU, which I was still having nightmares about and mostly staying awake at night. After this session I could not go back to the group. I tried to explain to my case worker why I could not attend the DBT groups, because of the trauma it had triggered. My caseworker ignored me and said that "DBT is beneficial for people with your diagnosis."

My refusal to engage with this group was constantly raised as evidence of me refusing treatment. No-one ever listened to me about why I was so distressed. Some time later the psychiatrist allocated this person to be my caseworker. She said it would help me work through my trauma. It did not. It made me even more distressed and made it nearly impossible to work with the service.

### **Person centred care**

I regularly felt throughout my engagement with [REDACTED] Mental Health that I was not seen as a whole person. They failed with some really basic things that would have made a difference to my interaction with them.

An example of this is the failure to use my preferred name, [REDACTED]. After my traumatic admission in May 2016 a friend told me that the Mental Health Legal Centre had helped them to write an advance statement. I made an appointment with a lawyer there and together we wrote my advance statement. One thing I put in my advance statement was that I wanted to be called by my preferred name, [REDACTED].

I had a further admission at [REDACTED] in 2016. My advance statement had been provided to staff but many staff refused to call me [REDACTED] even when I asked them to directly.

One nurse insisted on calling me "[REDACTED]" which I have never been called, even by my own family. She said if I wanted to be called [REDACTED], I would need to change my name by deed poll. Another nurse continually called me [REDACTED], saying that was what was written on the board in the office. When I suggested that he change my name on the board, he said "Excuse me, but do you own this hospital?". I answered that I owned my name and he interrupted and said, "No, you do not own this hospital?". I told him it was extremely disrespectful of him to not use my preferred name. In normal society, when someone calls me [REDACTED] because they do not realise I prefer the name [REDACTED], they apologise and call me [REDACTED] from then on. Yet in [REDACTED] I apparently had no say whatsoever in what I was called and was actually criticised for correcting people. I have no idea why [REDACTED] staff could not respond appropriately to what should have been a very straightforward issue.

Another issue I had was with care planning. I made many attempts to try and get a meeting with the whole treating team and my mother. Eventually an appointment was made with a psychiatrist I had not met before. It was an extremely upsetting and invalidating meeting: everything I said about my experiences over the past year were immediately dismissed as incorrect because they were not in my file. I had never seen Dr M before and all of her information about me was from my file or other people, yet she quoted from my file as though it was the only accurate account. Among her many upsetting comments were, "Why should patient transport be wasted on transferring you to Melbourne?", in response to my request to be treated by a specialist eating disorder unit, "Why do you think you're entitled to DSP when you've been refusing treatment?" and, "Psychology is a precious resource and shouldn't be wasted". When my mother said she had witnessed how badly I'd

been treated in the past and that I had been assessed many times as not have Borderline Personality Disorder by specialists, Dr M replied with a sneer, "Oh, yes she does".

I told Dr M that I wanted a proper review and a case conference with all relevant parties in order to formulate a proper treatment plan and get everyone on the same page and communicating with one another. I said this had been done when I was at the [REDACTED] and it had been beneficial. Dr M's response was to dismiss the idea, saying that they had very comprehensive case reviews on Wednesday afternoons. They not only failed to include me but also my family and other support people. As a result, they had only their own opinions and theories, which were completely irrelevant to my current needs and situation.

This lack of person centred care was present throughout the service including their phone triage. In April 2017 I was extremely distressed and as a last resort I called the triage number in the evening rather than simply self-harming and presenting to ED. A woman named S [REDACTED] answered and I said I was sitting on the bathroom floor with a razor blade. When she realised who I was she was critical of my recent attempts to get a copy of my community treatment order. I tried to bring her attention back to my distress, which was the actual reason for my call. S [REDACTED] said that she had 30 years' experience and she knew I was going to harm myself regardless of anything she said, so I should "just go ahead and do it". She said that in an inpatient setting she tells patients to do it in their room and make sure they clean up afterwards. By this stage I was crying so much I could barely speak. I asked why have a triage number at all and why had I been told by my case manager to call triage before self-harming, if that was her attitude. S [REDACTED] said perhaps my case manager thought I would "get lucky". She said if I called back after the shift change at 2200 I might "get lucky" with someone else. She then said she had a genuine caller on the phone that she needed to call an ambulance for, and she hung up on me.

During my time with the service I tried repeatedly to get specialist involvement in my care but the service kept directly or indirectly sabotaging it.

My experience at this service was so terrible that eventually I felt I had no choice but to move back to Melbourne to get out of their catchment.

### **Cross-border services**

In my experience cross-border services are very problematic as different laws apply depending on which unit you are in. This became very apparent to me in October 2017 when, due to a lack of beds in [REDACTED], I agreed to a voluntary admission in [REDACTED] (also part of [REDACTED] Mental Health Services).

On the morning of Tuesday 18<sup>th</sup> October 2017 I met my caseworker in the ED at [REDACTED] Hospital as I was wanting to be admitted to hospital. We did admission bloods and ECG, then my caseworker told me that [REDACTED] had no Low Dependency beds available. She said she did not feel I needed a High Dependency bed so I was being transferred to [REDACTED] at [REDACTED] Hospital. I did not have a problem with this because the plan was to go to [REDACTED] (a PARC) in [REDACTED] after my hospital admission and [REDACTED] was nearby.

At 1700 I left [REDACTED] hospital and was transported by ambulance to [REDACTED] hospital and admitted via their ED. A woman collected me from ED and took me to [REDACTED] House. As we were walking, she asked me if I'd been there before. I said no but I'd been to [REDACTED] a few times. She said that [REDACTED] is very different from [REDACTED] and that no smoking is permitted at all and also no phones, even in Low Dependency. I stopped in the hallway outside the ward and said that I needed my

phone to contact my family and support people. My parents had recently left Australia to return to the UK and were at that time on holidays in Europe until their belongings reached the UK. They were only contactable via email.

A nurse came out from the ward to the hallway and I explained why I needed my phone, or at least access to a ward phone and computer to contact my family. If I'd been informed at [REDACTED] that I would not be permitted to have my phone at [REDACTED], I would never have agreed to the admission, especially considering it was a planned voluntary admission and I knew that being further isolated from family and support people would only be detrimental during what was already a difficult time for me.

At approximately 1930 a group of 6-8 people surrounded me in the hallway and said I'd been made involuntary for refusing treatment. They said I was going into the HDU and I could either walk in or be dragged in. I said they could not possibly be serious and they could not do this over a phone. They repeated their threat to drag me into the HDU. I said I needed a ward phone and computer to contact my family, my lawyer and an advocate from IMHA, and was told "No, there will be no phone calls tonight".

I said that I had an Advance Statement which stated my brother should be contacted if I was admitted. They refused to call my brother and said my Advance Statement was invalid because [REDACTED]. Again, if I had been informed of this in advance, I would not have agreed to go to [REDACTED]. I was not given the information I needed to be able to make an informed decision about my treatment.

Countless times during the night and the following morning I said I wanted to be able to call my family, my lawyer and an independent advocate. On each occasion I was told no. I spent the night on a bench in the HDU; I was not given a room or told where the bathroom was. It was extremely cold and I tried to keep warm by moving my legs continuously. Because the staff had been so authoritarian and intimidating when they stormed out and surrounded me, I found it was easier for me to deal with them if I kept my eyes closed as this minimised their ability to intimidate me. Several times I was ordered to open my eyes, as though they had the right to control my body's organs. At one point I was apparently given a copy of my rights. I was told "legally we have to give you this piece of paper which has your rights on it". I said they had to do more than just inform me of my rights, they had to actually follow through with them. I said that allowing me to contact people was number one on their list, and I was not prepared to do or say anything further until they allowed this to happen. I was continually denied this right.

Late in the morning, someone who identified herself as a psychiatrist came into the HDU. I still had my eyes closed and at no time did I see her or anyone else during this incarceration. I told her that I would not be participating in any review or assessment until I was able to contact my family and lawyer and I wanted an advocate from IMHA to be present. I told her that I'd been asking constantly for this to happen and it had been denied. She tried to speak over the top of me so I yelled that I would not speak to her until an independent advocate was present. The psychiatrist left after a minute or two, yet she managed to write a full page of notes in my file for a Mental State Examination which did not take place.

A short time later a nurse informed me that I had been discharged. She said a taxi had been called to take me to the station, and she gave me a train ticket to return to [REDACTED].

### **Co-ordination of support**

I found it particularly difficult when I lived in [REDACTED] to receive co-ordinated care and support. Although I had case managers allocated through the mental health service, they did not see their role as playing a co-ordinating role in my care. Ideally I needed to have in place a GP, a regular psychologist and a dietician but it was very difficult to get these all in place and responsibility was largely placed on me to do that. At one stage, when I was struggling to get all of the aspects of my treatment in place, I sought the support of MIND, who also referred me to Partners in Recovery. I was allocated caseworkers through these two organisations which was quite helpful. However the community mental health service did not see engaging with these services as part of their role. They seemed to resent me seeking involvement from outside services.

It was only when I got a case co-ordinator through the NDIS that things really turned around for me. Her ability to connect me with other community based services that provided no or low-cost services (not just my NDIS funded supports) was really helpful. I was able to see a dietician and a psychologist for the first time in a long time. The mental health service had never told me about these options.

Co-ordinated support should be available to all people with mental health issues not just those eligible for NDIS funding.