Submission to the Mental Health Royal Commission

I am making this submission about our mother who was admitted to an aged psychiatric ward at [redacted] Hospital without consultation or involvement with us as her family and carers. We have serious concerns about her admission, treatment and discharge and particularly [redacted] Hospital's inadequate communication about our mother's time at the hospital.

I am following up on a range of specific issues with the Mental Health Complaints Commissioner who has formally accepted our complaint and is in process of contacting the hospital on our behalf. I understand that the Royal Commission does not address individual complaints but I believe some aspects of our mother's experience are relevant to the terms of reference of the Royal Commission, and may provide evidence to support improvements in the system.

Our concerns are based on our mother's, and our experience, and evidenced by her medical records which we obtained through an FOI request to the hospital. Our mother is aware that we are following up as a result of her experience, which she found deeply traumatizing. She is unable to lodge a complaint or make a submission herself, however, she has expressed verbally that she believes her experience was 'horrible' and 'should not happen to other people'.

Background

Our mother, aged 90, is a resident at an aged care facility in Capel Sound. She has dementia, diagnosed several years ago, is mostly blind, has significant hearing loss, has a heart condition and several other chronic conditions, and is quite frail.

Generally, her behaviour is stable and cooperative although over the last 2 to 3 years she has had a couple of episodes of instability where she became non-cooperative and mildly aggressive and made statements alluding to killing herself, although she has never attempted any self-harm. On one previous occasion she was taken to Emergency Department at [redacted] Hospital but not admitted. Following that assessment, she was seen by the [redacted] Hospital mental health outreach service while residing at her aged care facility.

On Thursday 21 March 2019 our mother was taken to [redacted] Hospital for an assessment at the request of her aged care facility. Staff were concerned about her mildly aggressive behaviour and refusal to take medication. According to staff they tried to contact [redacted] Mental Health outreach service who had previously managed her mental health by providing advice/assistance. However, their calls to [redacted] hospital on 21 March were not returned. The aged care facility also consulted our mother's GP who suggested she should be taken to hospital. We were advised of this decision and agreed it was necessary.

On a previous occasion when she was referred to [redacted] she was seen in the Emergency Department and then returned to her aged care facility and seen by the outreach service until she had recovered. During that visit to [redacted] I was present. However, during the recent admission, I was unable to go to the hospital, having only recently been in hospital myself. My sister lives in Perth. While our mother was in Emergency my sister and I had one or two phone conversations with the staff but without any indication of what they intended to do.

Our mother was admitted to a psychiatric ward under a temporary treatment order, on 22 March, but we were not informed or consulted about this action. We only found out she had been admitted when we rang the hospital to check on her progress. We were only provided with a copy of the assessment order and treatment order some two weeks later after we realised the basis of her admission and asked for a copy. Nor we were advised that a hearing had been scheduled with the Mental Health Tribunal for mid-April. We also discovered later there was no reference to our mother's Advanced Health Care Directive in the decision to admit her.

During the time our mother was in the hospital we were given greatly varying information about her treatment and discharge. It was extremely difficult to obtain consistent information about her possible discharge, quite literally varying from 'in a day or two' to '10-12 days' and other possibilities in between.

Initially our mother was content enough in the hospital and she was due for discharge on Friday 29 March. However, this was cancelled at short notice, again without consultation and she was kept in the hospital. Her medical records from the hospital clearly show that her mental and physical health deteriorated after her discharge was cancelled. During the next ten or so days she had a fall, broke her nose and received extensive bruising, contracted a respiratory infection, stopped eating and took minimal fluids, lost 8 kg, was exposed to the influenza outbreak that occurred on the ward, became non-cooperative and non-communicative, and was frightened by the other patients on the ward and the general environment. In her view she was being held against her will, was unable to meet the behavioural objectives that were imposed, and believed she would die. If we had not forcefully intervened on her behalf and pressured the hospital to discharge her I believe she would have died. When she was finally discharged some 10 days later, the doctor on the ward agreed she was being discharged to palliative care.

By the 6 April we were so dissatisfied with the situation we wrote to the hospital expressing our view that the treatment was inappropriate, ineffective and counter-productive, and was putting her life at risk. We requested that they find an alternative place to treat our mother. They never responded to the email. In subsequent meetings the hospital at times adopted a sympathetic tone, explaining our mother's situation as the result of 'an unfortunate and unforeseen' series of events. At other times some of the hospital staff were clearly annoyed, highly defensive and disrespectful when we questioned decisions or sought information. However, one of the medical staff acknowledged that our mother's situation was a case of 'institutional failure' (quote). Several ward nurses also told us 'your mother should never have been admitted to this ward' and 'it was inappropriate for her to be admitted' (quotes).

Although the ward was designated as an aged psychiatric ward it seemed a very inappropriate facility for the treatment of a 90-year old, frail, blind and deaf woman with dementia. Our initial impression that the facility was inappropriate was reinforced during extended visits when we observed the sorts of behaviour our mother had had to deal with for over two weeks, including a man naked in his room, a woman trying to climb a lifting device, another having an imaginary phone argument, a man urinating on himself, all against a background of periodic shouts, and at times extended periods of screaming by patients. I provide these observations not to disparage people with illness but to highlight that our mother had had one night of uncooperative behaviour and yet she had spent over two weeks on a ward with people who demonstrated what to her was strange and frightening behaviour. For much of that time in the hospital she was generally stable according to both her medical records and nurse comments. What had happened was that she had become traumatized, deteriorated greatly in her psychological and physical condition and she appeared unlikely to recover.

In several meetings we insisted the hospital find an alternative treatment facility or discharge her back to her aged care facility which supported our request and was willing to have our mother return and be managed by her GP. On 9 April we were informed that the hospital would review our mother and that she may be discharged. In consultation with the medical doctor involved in treating our mother, it was agreed to significantly reduce her medications because she was effectively returning to palliative care. We were advised we could attend the assessment at around 11 am on 10 April at the hospital. However, the morning of the assessment we were contacted at home and told the assessment had been done without our involvement and that our mother would be discharged.

Over the next several weeks and against the odds our mother has made considerable progress due to the care by her GP and the staff of the aged care facility. However, she was deeply traumatised by her time at [redacted] hospital. She described it as a 'terrible ordeal', that she was constantly afraid, and had no idea why she was there or what she was supposed to do while there. She commented frequently about being upset at the behaviour of other people and was distressed that she felt they needed help but she couldn't

help them. She was afraid of the screaming from other rooms and thought she would die. On return she would not eat. Nursing staff at her aged care facility said they thought our mother was in shock. It took several weeks before she began eating a reasonable amount. She still confuses her home with 'that prison place' and confuses the people and events at her aged care facility with her time at [redacted] which in her mind was 'a horrible time'. Although she has recovered somewhat and is now eating and drinking more consistently she has not returned to either a physical or mental state as good as she was prior to her admission to [redacted]

Our concerns

As a result of the experience of our mother at [redacted] Hospital we have a number of concerns about the admission, her treatment and the discharge process.

Admission

- [redacted] Hospital Emergency Department did not recognise our roles as our mother's carers during the admission process. We were not consulted about the admission or that she was being admitted on a compulsory treatment order or informed of the decision, or provided with any information about the compulsory treatment order. The hospital had our contact information and we are listed on their records as carers. The doctors in the Emergency made no attempt to inform us their decisions which is deplorable.
- The treatment order shows no acknowledgement of our mother's Advanced Care Directive.
- The doctors and psychiatrist involved in the admission process disregarded our mother's rights under the Mental Health Act:
    - if she was informed about the treatment order she could not have understood what was happening or what the order meant.
    - she was not given a copy of the assessment order, the treatment order or the brochure explaining her rights under the Mental Health Act.
    - if she was informed of the risks, she could not have understood them.
    - she would not have known about or been able to request a less restrictive form of treatment.
- Particularly given our mother's inability to understand or consent to her treatment, this should have prompted the hospital to seek our involvement as carers but we were not informed that she was placed on a treatment order, nor were we given a copy of the orders, nor provided with information about her treatment under the Mental Health Act, or advised of the Mental Health Tribunal hearing.
- Our mother's medical records show that the sections where doctors are required to indicate who was consulted and informed about decisions are completely blank.
- The treatment order requires a determination that the person's needs cannot be provided in the community. Our mother has a right to the least restrictive treatment but this was disregarded without explanation or consultation with us as carers or with the aged care facility where she lives. Given she had previously been treated by the hospital outreach service, it would have been more appropriate to have provided treatment using a community approach, in collaboration with her aged care facility, who never requested for her to be admitted.
- In summary, our mother was denied her rights under the Mental Health Act. As an elderly person with dementia the hospital failed to treat her with respect or to involve us as carers in the decision-making process.

Treatment

- Our mother's physical and mental health deteriorated significantly during her time in the hospital. The only explanation for this deterioration was that it was the result of an unfortunate and unforeseeable set of circumstances.
- All the advice we have been given about dementia has emphasises the need for stability and the importance of a familiar environment and people. However, the psychiatric ward was the opposite

of this – noisy, unfamiliar, threatening, and stark. The risk of injury, infection or deterioration as a result of compulsory treatment was obvious but seemingly ignored or downplayed.

- In the ward, our mother suffered a respiratory infection, broken nose, facial lacerations and bruising, loss of weight, was exposed to influenza, became non-communicative, became more negative, and refused to eat and drink or take medication. At the time of discharge, her physical condition had deteriorated greatly and her mental health was worse.
- This facility seemed to us to be entirely inappropriate for a person of our mother's age and condition, and entirely inappropriate as an environment to stabilise the behaviour or treat an elderly person with dementia. In fact, her health deteriorated and no coherent treatment was developed. On the contrary, the treatment exposed her to numerous foreseeable risks which actually eventuated, and caused or contributed to her deterioration.
- Overall her hospitalisation is best summed up by one of the doctors from the treating team who commented that our mother's situation was concerning and a case of 'institutional failure'. I was shocked by this frank admission but also motivated to press our concerns given that a member the hospital staff had seemingly acknowledged them.

Discharge

- The discharge review which were advised we could attend and were scheduled to attend, was done earlier than scheduled and without explanation or consultation. The treatment order was revoked. While on the one hand we were glad she could be discharged, we have a number of concerns about the discharge.
- Her medical records indicate both her behaviour and physical condition deteriorated significantly during the second week of her admission, as described above. She was assessed as 'high risk' on nearly every assessment, twice a day for the week prior to her actual discharge. Her records indicate that she had stopped eating, had minimal fluid intake, had a broken nose and a respiratory infection, was non-communicative, and non-cooperative in taking medications. However, remarkably she was discharged and the assessment rated her as moderate risk and not requiring treatment under the Act. In nearly all respects both her physical and mental state was far worse at discharge than when she was assessed for admission. Her discharge begs the question, if she was suitable for discharge, what warranted her admission, particularly against her wishes and without consultation with her family?
- It seems that she was admitted without proper process or regard to her rights, without consultation with us as carers, subjected to unrequested hospitalisation during which her condition deteriorated markedly and was then discharged because we pestered the hospital with questions and complaints. In seemed easier for the hospital to assess her as no longer requiring treatment and discharge her even though in every respect her condition was worse than when she was deemed 'mentally ill' under the Act.
- We have had no explanation of either her treatment, cancellation of her initial discharge, or the reason for the final discharge. Her aged care facility has never been provided with the treatment plans we were advised had been prepared.
- A clinician from a part of [redacted] aged mental health outreach service visited our mother several times after discharge at her aged care facility and rang me a number of times. My impression was that these contacts were only partly about monitoring our mother's progress after discharge and more focussed on assessing our level of comfort with her return to her home.

Concluding comment

- In summary our mother has made had a patchy recovery. Overall, the outcome of her treatment is that she is worse both physically and mentally compared with the time prior to her admission. Alternative options of less restrictive treatment were seemingly ignored or dismissed without due consultation with us or the aged care facility. I cannot say that our mother's deterioration is entirely due to her admission and treatment but it seems significantly correlated with it. In our view the adverse consequences of her treatment have far outweighed the benefit. We believe she would have died, probably by starving herself, if she had not been removed from hospital.

- What is beyond doubt is that [redacted] Hospital failed to respect both our mother's rights by admitting her in the way that occurred, and they acted against her interests and our priorities by failing to inform us or involve us in her admission, treatment and discharge.
- The hospital also failed to communicate effectively. Despite appearing to be concerned and sympathetic, the conern seemed superficial and more often we experienced confusion, contradiction, lack of information and at times obstruction, defensiveness and disrespect.
- I believe that the staff at [redacted] Hospital were probably for the most part, trying to do their best, but in admitting her they failed significantly to respect the rights of our mother or us as carers, that the treatment was both inappropriate and counter-productive for an elderly, frail woman with dementia, and that the hospital failed completely in their communication and engagement of us as carers.

[redacted]
18 July 2019