

## Supporting Document

**I am the main carer for my younger brother, who is 71 years old and has a 48 year history of a diagnosed mental illness.**

**Although I have been a part of our family's care and support of my brother since I was young, I have been his main carer since [REDACTED].** In the early years of his mental illness it was only the police who would show up when he was in crisis. My parents were incredibly caring and compassionate people, I don't know how they did it for all those years. Our father passed away in January [REDACTED] and by July my brother had another crisis and was in hospital for a month. In [REDACTED], I was overseas pursuing my career when my mother called saying she could no longer handle it and needed me to come home. It was at this time that I gave up my career to come home and resume the role of full-time carer for my brother and my mother. When I came back my brother had just been discharged from hospital and he knew I had come back to take care of everyone.

**It was very difficult managing caring for my brother and mother,** as he did not understand the process of my mother's care or what was happening to her as her health deteriorated. I couldn't handle both so we looked for somewhere for him to live but he was so comfortable at home, a member of the family, involved in all activities and very close to our parents. We could not find anywhere appropriate for him. He was very particular about the places, the cleanliness, privacy and suitability of occupancy and I respected this. He deserved better. This was really tough on me.

**People often say to me that my parents should have taught him to be more independent but what they don't understand is there was no services or support back then ( in the late 1970's to late 80's..** My brother's first hospital admission was to [REDACTED] My brother's crisis was unmanageable by the family GP who said "someone needs to go with him to admit him" and as my parents were both devastated, confused, and emotionally drained by the events of the crisis I had to be the one to do it. I had to be the one to do it. My brother still remembers that as I was the one who put him in hospital for the first time.

**[REDACTED] was like a prison and the psychiatric staff blamed the family,** so we came home and did what most families during that time did, we handled it ourselves. At this time, there was no multicultural understanding, no in-home support or family support. We tried so many things, there was no pressure to continue his final year of engineering study, there was no pressure to work, and we tried sending him to live in the country, but nothing worked that convinced us of the possibility of recovery. Relapses and hospitalisations continued.

**As a family we experienced a lot of stigma and a lot of consequences for how we stuck by him and supported him, and it's still there today.**

Since my mother passed in 2004 I have been my brother's sole carer and trustee. **This blurring of our sibling relationship and carer relationship impacted our relationship greatly** as my brother perceived that I was cheating him out of his inheritance by becoming his trustee.

**My brother has a history of medication non-compliance and limited insight into his illness,** as such he has been on several community treatment orders over the years. My brother craves a normal life, he wants to be like everyone else, but his mental illness has impacted him greatly and resulted in social isolation. After attending one of his local cafes when unwell, he has been banned from it. And still today keeps away, not understanding why he is being treated like this. On the other hand, another café has developed a strong bond with him, he goes daily to lunch and coffee there, they are somewhat protective of him and know his sister is around if there is any trouble. **As a carer I am constantly mediating relationships and understanding with his neighbours, I've always tried to be an advocate**

**for him whenever I perceived an issues, despite having no support.** He keeps himself very isolated, I think it's the stigma he feels. He wants so much to be a part of normal life, but he can't cope, it becomes a bit too much for him. We don't have lots of family, and have had past experiences where family have cut ties because of his behaviour. But he doesn't understand why. My brother is a very intelligent man, but he feels left behind, as he's not up with computer technology, yet he remembers and knows a lot about engineering and building matters from his years of study. A major issue now is his lack of motivation.

He used to be supported by the mobile support team (MST) from [REDACTED] Community Health Service which supported him throughout several hospitalisations, as well as to avoid further hospitalisation and achieve some quality of life. **They knew him and his patterns and he knew them – there was a good relationship there.** When he was transferred out of MST's care because of his age (65 and above) it was essentially "goodbye", and he no longer received the level of support necessary to keep him well and in his community or keep myself as his carer safe and supported.

I have been extremely disappointed with the level of care and support my brother has received since being transitioned from Adult Mental Health Services to Aged Psychiatry Services at 67 years of age. The following summarises the key issues regarding my brother's care since 2014.

**In 2014 I sent a letter of complaint to [REDACTED] hospital which highlighted the issues arising throughout this transition process:**

- There was no preparation, no communication with myself or my brother, which added to his crisis. When he saw where he was being admitted to he became highly agitated and this resulted in my brother being moved to [REDACTED] mental health unit for a few days for additional support. This was a setting he was so familiar with and known by staff, even friendly with the cleaners.
- No recognition of my brother's significant mental health history
- Aged services and support put in place were not enough – there was no new team, just the psychiatrist and one other, the case manager. Due to staff shortages they could not do anything outside their role and therefore could not take more responsibility for his care.
- There was a lack of support for myself as his sole family carer. There was no carer consultant, no family support group meeting, all was new for me too. We were dropped off the adult mental health services to ....something unknown??
- Poor management and understanding of his Type 2 diabetes which put his physical health at risk
- He was discharged from adult services whilst still unwell and unstable, as such I as his carer was left to manage his deteriorating mental state despite asking for help several times from his case manager and treatment team
- In the aged care mental health facility there were no activities, no programs, and it was limited to sitting in front of the TV or sleeping. There were no programs or involvement with groups which facilitated recovery and prepared patients to return to the community.
- The privacy was a big issue, other elderly and mentally ill clients would wander into his room, and touch his personal items or take things I had brought in for him when I visited.

These issues resulted in a report to the Mental Health Complaints Commissioner. With a representative support I arranged a meeting with the representatives from [REDACTED] Aged Mental Health & Residential Care Services in 2015, where the issues were discussed and the services acknowledged the following:

- **Transition from adult to aged MHS:** [REDACTED] agreed to review communication and the process of transition with the client, and to hold separate meetings for carers to be aware of the transition plan, including visiting the facility
- **Discharge processes:** [REDACTED] acknowledged their failure to check his medication history and non-compliance before discharging him without medication oversight
- **Activities program during transition from adult to aged:** agreed to review the range and appropriateness of activities available for people over 65 with mental health issues, and to not assume they are the same as those people in their late 70's, 80's and above. The point being, age appropriate and ability appropriate.

- **Hospitality services & environment at Normanby unit:** agreed to review meals and timing, especially for diabetic patients, and to look at options for in-room storage for important personal items e.g. radios and activities
- **Ongoing care:** ██████████ stated that adult services can no longer support him. Aged services said they will look into volunteer services/support, however they must respect his right to decline such services. Yet, there was no consideration given to assess the individual situation, that is, with only one older sibling as the carer, they did not consider how much dependency is placed on me as the family carer or understand his limited insight into the limitations of a family carer.
- **Improved engagement with carers in aged mental health services:** ██████████ acknowledged carer support networks/programs exist but barriers such as personal, economic, transport exist which limit carer involvement and continued program support.

**While I appreciated the opportunity to call this meeting and have these discussions, it should not have had to come to this.** As my brother's main support for over 20 years, I should have been consulted about what supports he needed as well as what I need as his carer. I will not be around forever and I want to know that there are proper supports and plans in place for him. I want to know someone will check in on him and make sure he is okay. I expected he will be treated well and with dignity as a good person, and not be abused or taken advantage of, or be manipulated.

**Since the commissioner intervened my brother has had the same case manager, which has provided some level of continuity of care, however he's more of an administrator.** There is dependency on him, and some anxiety results when he goes on vacation or takes leaves. It is important to tell me who covers and who is my contact if I need help. Now, my brother receives just 1 hour a week of support from the aged psychiatric service. I have organised a private arrangement with a personal carer service for every night of the week for 1 hour, so they can provide medication supervision and companionship. I always try to ensure there is a personal carer there who he knows and feels safe with, but it can be difficult. If I have a concern, I call his case manager and collaborate with him so he understands what is going on.

My parents worked very hard to ensure my brother would be able to live a comfortable life when they were gone. As such, he is considered a public retiree which has meant he has fallen through the cracks and is at high risk of social isolation. Despite the case manager being involved I am still the one who organises private carers, in-home care support for him because without these people coming to see him, he would have very limited connections and social outlets. **Isolation is a big concern that I have for my brother, as I do not visit him every day. He would find that an invasion of his privacy but I try to keep our connection going well.**

**My brother has a love of music, and he connects with some support workers on this, but they don't support his with his other daily living tasks when he needs.** I've called the agency to complain that they do nothing. However, my brother can be particular about his things so he may tell them no, and therefore they do not provide the in-home support they are meant. My brother usually stays at home unless others bring him out and he agrees to it. It is also challenging to find male support workers which my brother prefers as he has very few males in his life. He can be a very sociable person but some of his friends are also unwell, so it doesn't promote a healthy environment for him, especially when he has been on the verge of an episode.

We have had some bad experiences where some personal carers have turned up drunk and acted in a very inappropriate manner! I have also had a very bad experience with a community mental health professional who visited him when he was an inpatient, who took it upon himself to start the VCAT process to get my brother a state trustee, instead of me being his trustee. My brother was very unwell and suffering from paranoia at the time, yet the worker encouraged him to sign forms to proceed with the VCAT process, for which I had to prepare a lawyer and case for. Unsurprisingly, when this case went before VCAT the judge sided with me and said it was extremely inappropriate that this staff member initiated this process without consultation. He was very sheepish and his behaviour was deemed unprofessional by the presiding judge.

**As carers, it is always confronting to see your family member go through an episode but we learn to go through it because we have to.** There is a huge emotional component to caring, I certainly know my parents went through it and it took a toll on them, mentally, physically and emotionally. It is especially hard to know what to say to him when he has the tremors from the medication, which he has to take as he is under a CTO. The side effects of the medication cause issues with his diabetes – it's just an awful cycle. He knows his medication causes him health problems, including weight gain, and there is always either the fear that he will stop taking his medication – for which the consequences can be devastating.

**There have been some positive experiences with the system, such as:**

- Initially in the [REDACTED] mental health unit I received great support through one of the carer consultants. We need more people like this funded and available to family carers
- IN the last two years the carer support personnel at MIND were wonderful, for 6 weeks a carer support person came and helped me with shopping, errands and talked with me after I had hip surgery for a fractured femur after a fall

**To the royal commission, I make the following recommendations:**

- **Family's need information, support, and opportunities to share:** For example, carers groups, activities and outings. Every one of us is experiencing that emotional distress, some carry it better than others, but you can see it in everyone. When I've connected with someone and we share experiences, sometimes I come away thinking "it's not too bad". I try hard to accept in peace where I am and carry on.
- **We need community programs that don't make a distinction between self-funded retiree and public.** The issue is isolation, all these eligibility criteria mean my brother is isolated from the programs of aging adults. We try to pay for community transport but they still say no and so he remains isolated. Due to his illness he does not have these supports or connections within his life and we cannot access the public programs because he is categorised as "self-funded" as my parents made the commitment to look after him. There needs to be other categories so that people in the future can access programs, even though they may have some family support, it does not mean that the family can do it all.
- **Look at the My Aged Care:** where do they consider the physical and mental state of the person? Such as my brother who is on a CTO. They just look at the assets and make a judgment without considering the persons physical and mental health history.
- **Community awareness of severe mental illness:** if we are encouraging people to live in the community we must broaden the understanding of the community, to reduce the stigma. We need more support systems within the community and avenues for me or others to say and act on when there is an issue. I've called the helplines, you repeat yourself over and over again, but nothing conclusive comes out of it.
- **Need for in-home support services that understand and staff are trained in mental health,** so they are understanding of times when the client is unwell. Because the staff just stop coming or don't do their job properly. Also, in the client support staff relationship, consistency and familiarity is very important so that the family is comfortable with staffing assignments and isn't left with strangers or no back-up. There's been times when they cancel and I've had to go round every night so that he has someone visit and help him.
- **Companionship is so important.** Knowing there is someone visiting him is reassuring to me, as it ensures I will know if there is an issue but I don't have to be there 24/7 which means I get a break too.
- **Refund MIND's family and carer support program.** It has been defunded and is stopping this November, without that the only support is his case manager, so there is nothing for the family now. It's been a break that I look forward to, especially around Christmas time as we don't have a lot of invites from family.
- **More sibling carer groups:** It has been difficult to find sibling groups, to connect with people with the shared experience.
- **Better communication with family and clients when staff move on to new roles.** They don't realise how significant they become in our lives, to us it's a link keeping me connected to others. It is more than just looking at the services of my brother.

- **Funded & accountable community supports:** There are some organisation out there that advertise programs, such as companionship for the mentally ill, offering hope to the family carers that their loved one is helped against isolation and loneliness. But often when you call, you are told they need to recruit people. They still advertise despite not having volunteers in place. We need some guidelines or criteria to monitor giving this kind of false hope of assistance to family carers.

I hope that the Royal Commission takes this opportunity to change our system seriously, for the sake of people like my brother and I. For me, the future is a big concern. I'm trying to keep him at home as long as possible, but I don't know what is going to happen. I'm even having to think of planning my own funeral, as my brother has said he won't be able to do it on his own but he would want to make sure it is done properly for me. But that's the reality of things for aging carers.

My brother lives in the past, with pictures of his friends from his youth. He craves a normal life, he says "I haven't killed anyone, I'm not a bad person", he doesn't understand why he can't have the life he wants.

He deserves to have good quality of life, with social outlets and connections, and adequate care and support.