Supporting Document for Individual Formal Submission to the Royal Commission into Victoria's Mental Health System

I am a mother who has been supporting my 26 year old son for the past 8 years.

Since he was diagnosed with schizophrenia, it has been 8 long years of torture, of struggling to get help. I have been forced to watch my beautiful boy's life deteriorate in front of my eyes.

At just 26 years of age he has aged and experienced so much. My son has been through a lot of trauma after seeing his father die in front of him 1.5 years ago. He has been severely bashed on public transport and during a recent stay in an inpatient unit. I worry he has an acquired brain injury as a result but we have not been able to have him assessed. He has now developed an alcohol dependency and experiences ongoing medication complications from inconsistent treatment and management of his illness.

My experience as a carer is one of being ignored and of not being listened to. I feel so disempowered and exhausted from constantly battling to get my son the support and care he deserves.

When my son goes off his medication he becomes psychotic, the neighbours complain and at time it's been so bad I have had to sleep in my car. There have been hundreds of nights with no sleep, of not being able to work because I had to care for my son. The past financial year I earned $4000 because I was too busy and stressed fighting for my son to get help. There have been thousands of phone calls – 20 to 50 calls every day - yet I have been unable to get my son the help he needs. On a number of occasions he was discharged back to me when it was not appropriate.

Now, my son lives in supported residential services (SRS) accommodation where there is no quality of life, but I can't survive with him at home; I'm exhausted and it was our last resort. It is an absolutely horrible place and unjustly expensive, my son's SRS costs $400 per week! We have tried alternatives such as boarding houses but my son did not have enough life skills and the boarding house was a disgusting place. When he was first moved to a boarding house, the social worker at the time inappropriately told my son "I'm taking you to a crack house". Despite this being completely unprofessional, sadly it wasn't far from the truth. The boarding house was not a safe place for my son who has a mental illness, alcohol dependency issues and has a history of trauma from being physically assaulted.

I have a nursing background, so I understand what it can be like for workers, but the system and its workforce must do better.

The main issues I have experienced are:

- **Inaction by CATT:**

When I call CATT, they say call the police. I have had experiences where the police requested someone come to the home to do a mental health assessment but they refused. So the police left me to deal with my son on my own. There are several CATT workers who need to be moved on, they are clearly burnt out.

- **Referring mental health issues on to the police and ambulance services:**

My son has threatened to kill me before when he's been psychotic and off his medication and I have had to take out an IVO. While I have had some good experiences with police and ambulance, not all understand mental illness and they shouldn't be the main point of call for people who need specialised treatment for mental illness. Police have fined my son for walking close to the freeway when he was suicidal. Instead of getting him help, he spent the night in jail. But without the police my son would be dead. I am grateful that the police were there, however it is not their job. We need earlier interventions.

- **Treatment teams and mental health workforce ignoring and not supporting family:**

During my sons last admission I continuously tried to contact the social worker, I could never get a hold of him. When he finally did get back to me and I booked appointments, they all ended up cancelled. I was unable to discuss my son's treatment with him. It is always a battle just for basic things. I have tried to tell staff when he is hallucinating because he talks to me about it but they just don't listen. I'm very concerned about his participation in online communities and that he could be negatively influenced by people to do something terrible, but I've had an awful time trying to get help or find anyone that will listen to my concerns.

The system needs to understand how much this caring role impacts my relationship with my son. When I am the one who has to take him to appointments, contact the police or the CATT, he becomes suspicious of me.

- **No respite for carers other than short hospital admissions:**

A few months after my son's father passed away my son ended up in hospital again, at the same time my mother was seriously ill. When the hospital started to discharge him to me I asked if he could go to PARC because I needed to go and visit my mother who was living in the country several hours' drive away. PARC would not accept him. My mother died 10 days later. I wasn't able to spend time with her and say goodbye because I couldn't leave my son alone and he was too unwell to come with me to visit her. It is so hard for carers, there's a lack of accommodation to give you any respite and if there is it's only short-term. I have complained to the Mental Health Complaints Commission, they tried to help me but they are very busy with consumer complaints and do not have enough resources to support everyone.

- **Complete lack of compassion and consideration of trauma:**

There was a complete lack of compassion from staff when it came to supporting my son so I could see my mother before she passed. My son has also experienced this in the expectation that he catch public transport to treatment and appointments, despite his history of trauma after being bashed on public transport. When he refuses to take public transport to appointments, they label him "non-compliant" and "disengaged". Because of this he has been unable to access important services as he is seen as disengaging with existing services.

- **Blaming and stigmatising families:**

Families don't get the blame in cancer services. The difference in the level of care they receive in comparison to the mental health system is profound, they receive proactive and family inclusive services.

In comparison, I have received many inappropriate comments from staff in the mental health system who have labelled me a "neurotic" mother when I battle to get my son support, with staff making comments such as "you must be feeling guilty". It is unacceptable to blame and stigmatise families for wanting to get help for their family member. Trying to get help when my son was a teenager was really tough, but it is so important to get help early. His outcome could have been much better if he had received help earlier.

As a carer I feel the stigma, blame, criticism, exhaustion and sadness of fighting while I have to watch my son deteriorate.

- **Inappropriate discharge:**

My son is currently deteriorating further into a suicidal state but there is talk of taking him off the treatment order. My son at times ends up in the emergency department and sometimes they don't notify me. Previously, he was suicidal and took some poison. Within 48 hours he was discharged from hospital back to his SRS accommodation with no support organised to get him back to his accommodation, as I was not even notified of his discharge. He has been discharged from emergency departments inappropriately. There have been times when they have conducted mental health assessments after he has been highly medicated and subdued and therefore he is deemed not at risk. This is not good enough and it is not safe.

- **Overloaded and under resourced workforce:**

There are some good supports for my son and carers, such as MIND and the Mobile Support Team (MST), but their case loads are so big they simply cannot effectively support everyone. As a result of the overloaded and under resourced workforce, clinicians often give up and discharge consumers from their service before even giving them the chance to build rapport. Unfortunately, this means that the only way to get any proper access to and support from services is through a treatment order, because if there is an order in place they have to help.

- **Stigma of dual diagnosis:**

My son has experienced stigma as a result of his dual diagnosis with mental illness and AOD which has impacted the treatment and support he receives. This should not be happening.

- **Ignoring physical and other health needs:**

After being physically assaulted multiple times I believe my son has acquired a brain injury but despite my requests he is still yet to be assessed. Despite living in "supported" accommodation there's no focus on supporting personal hygiene or other health needs, such as my son seeing a dentist. My son was a beautiful, sweet boy but now he struggles to do these things for himself and so nobody wants to go near him.

There are some things that would make a huge different to my son and my life, including:

- **Outreach:** more mobile support teams, especially for young people who may not have the motivation to get themselves to services. This includes CATT's that are willing and able to visit when needed!
- **Listen:** to parents, to siblings and family. They are the expert. We have the life experience as carers for our family member. Don't talk down to us.
- **Strengths:** Look for strengths and positives in the people who are being treated. Give people hope, even small things like clean clothes or nice comments can make a difference. Our current system and approach is so dehumanising.
- **Respite & support:** We carers need a break, we need support but we also need our family member to get support so that we can have a break and not have it impact our family relationships.
- **Compassion:** the system, the service and the workforce need to be more compassionate and understand the immense pain and stress that families and people like my son are experiencing. Workers need patience and understanding to properly engage people with mental illness.

To the Royal Commission, please understand I don't want my son dead, I want him better.

There are times I have wished he had a physical disability just so he was manageable and I could get help to care for him. It shouldn't be this way.

Support from Tandem during this Royal Commission process has been important for ensuring carers have a voice. It has been so empowering to be listened to after being disempowered and almost destroyed by the system.

Please understand, we carers are so drained. Caring impacts our own health and wellbeing. We do not have enough support. I hate to say it but at least families got a break when they knew their children were safe in the institutions.

Recently, the carer consultant at the [redacted] took her own life and honestly, I understand it.

Carers are at the end of our tether with this broken system.

My daughter has lost her father, her grandmother and now her brother to the mental illness. She has also missed out on care and attention due to me being busy caring for her brother. So much care goes towards caring for the sibling that is unwell. Siblings need support too.

We are supposed to be the most liveable city in the world. Something must be done; this is not good enough.