

Supporting Document

I am the main carer for my father who has bi polar and a history of alcoholism. I did not realise I was what is known as a 'young carer', until my father had a difficult hospitalisation when I was around 20 years of age. Both my parents are from England, as such we have no family here, no family friends and no support. My brother and I have been the only enduring supports in my father's life and I have been the one to take on the vast majority of the role of 'carer'.

Mental illness first impacted my family when my father had a "nervous breakdown" when I was 4 years old and my brother was 6. This time of my life is very much a blur but I can recall memories of finding my father in a corner of the bedroom crying uncontrollably. I remember trying to comfort him by showing him what I had made for him at school that day. He was screaming and could not look at me. Other times I remember the alcohol, and the screaming and anger that followed. I remember my brother keeping me in my room. I couldn't understand why my father was so sad and why he sometimes seemed afraid of me. **When my father was well he was an amazing dad, but I have very few memories of him being well when I was a child.**

When I was 5 years old my parents divorced. My parents' divorce was very toxic and to this day they still cannot speak to each other or be in the same room. My mother was and still is traumatised from the experience of trying to support my father as his undiagnosed mental illness spiralled out of control and he used alcohol as his coping mechanism. **He was an abusive and intimidating man during their marriage, yet presented as the perfect husband to outsiders looking in. In the decade following their divorce there were several intervention order's put in place as my father became very scary when manic, intoxicated and untreated and unsupported by services.**

After the divorce my mother had majority custody of both of us, but we would go and live with my father at least every second weekend. This arrangement lasted throughout my childhood and teenage years, though the episodic nature of my father's illness (and drinking) meant sometimes we did not get to see him because he was too unwell. **These long periods of not seeing my father or him an unhealthy person to be around has had significant impact on mine and my brother's lives, as well as our relationship with our father.**

It was not until I was 16 years old that I found out my father had a bi polar diagnosis. At this time he was very unwell and he had been told by a clinician that he should talk to us about his mental illness. While I am sure this clinician had the good intentions of facilitating better family connections and communication, the result was my father handing me a folder called 'bi polar' and he told me "you should read this because it is what I have and you'll probably get it too because I've already fucked you up so much". **As I sat and read that folder, I was overwhelmed with fear and anxiety.** I believed there was no way to escape this fate. I read about the worst, most debilitating symptoms and impacts of bi polar, the rates of successful suicide, of how I would likely follow in my father's footsteps and I felt there was no way to escape this. Though, I have educated myself since, I still struggle with anxiety and in the last year have been diagnosed with my own mental illness.

Throughout my childhood my father had close to a dozen suicide attempts. Some of this I know because my mother told me of the times she found him, others because I have pieced together the snippets of my fragmented memories. He tried to hang himself, overdosed several times, and crashed his car – into trees, he rolled off of freeways and drove into bodies of water.

As a child I remember visiting my father in hospital after he had overdosed. We were told he was just ‘really sick’. I remember being so scared of all the tubes attached to him and didn’t understand why he just cried and would not speak to us. No one at the hospital sat with us to explain. No one ever gave us information on mental illness. **No one identified that he had children that needed support.**

I believe it was assumed that we were ‘okay’ because we were with our mother. This assumption was dangerous and harmful. It left us, unsupported, struggling to make sense of what was happening, with a traumatised single mother who did her best, but did not have the capacity to take on this burden too. We grew up confused and experienced additional trauma as a result of never being identified and supported by mental health services.

From speaking with my father, I know that throughout his numerous hospitalisations from suicide attempts, he was treated like an addict and not like a person with symptoms of an acute mental illness. They failed to recognise these as suicide attempts, instead treating him for ‘work stress’ and attributing overdoses and car crashes to ‘tiredness’ and ‘having a bit too much too drink’. As such, on several of these occasions he was discharged from hospital without any form of mental health support. Before my father had his ‘breakdown’ he was ranked BMW’s top salesman in Australia and became the youngest person to ever achieve this. He was and still is an incredibly intelligent and gifted individual but the untreated bi polar and alcoholism has taken its toll on his life. As a child we lived in more than 20 homes, across both parents, this level of instability had huge impacts on all our lives. **My father has had to recreate himself so many times. While it is a credit to him that he has been able to do so, each time has cost him his health, his job and social connections. He has very few friends left now and battles social isolation and loneliness, especially when on the brink of another episode.**

My most feared memory is that of when my father was driving us in his van and he began driving it at the lake we were passing. I remember asking him what he was doing as I thought he had lost concentration but I realise now he was depressed and driving at the water with the thought to end it for all of us. I would have been about 8 years old at the time, my brother was in the back and did not realise what was happening. My father stopped the van at the water’s edge and we stayed there, quietly, for some time before we drove on. It was around this time that I believe my father was homeless because we were ‘on an adventure’ which meant living in his van and sometimes couch surfing with his various friends. I have never been able to speak of this to anyone, especially my parents. I feared that if my mother knew, we’d never be allowed to see him again, and if I ask my father about it, it may be enough to push him to try to suicide again, as his biggest trigger is that he has failed us as a parent. **When he is very low, he often tells me we would always have been better off without him because he knows how much of an impact his mental illness has had on our family.**

It is for this reason that my submission needs to be anonymous and not shared publicly in full, even once de-identified (I am happy for de-identified excerpts to be shared publicly). I cannot risk the impact that my

sharing of these memories may have on my father and our relationship. Our relationship is far from ideal, but I hope that as he continues to recover I will get to have him in my life for a long time to come.

Our current system promotes suffering.

I wish for the commissioners to understand the rippling impacts of our vastly inadequate system, so that the commission will put forward recommendations that will sustain a new system which promotes functional and relational recovery, for the whole of family and community.

I want the Royal Commission to know what it is like to be a 15 year old and to sit and contemplate what you would say in your father's eulogy. The shame you feel as a carer, a daughter, after thinking 'I wish that he would succeed in killing himself so that all of our pain would go away'. I have done this so many times I have lost count. I have been so sure that I would never see him again whenever I get that strange text or phone call, or when he simply goes missing. I have, since the age of 16, come to accept that if he does succeed in taking his own life, that I will not be angry with him. Because I know how much pain his is in and I know how hard he has tried and failed to get help. I have had ex-partners ask how I can stand by and watch my father destroy his life over and over again, but they don't understand that it is his untreated illness destroying his life. Many people within the community lack this level of understanding, which is why I have never spoken to others about my father's illness and its impacts on me.

Really, it is the system for which I am most angry with, though describing it as a 'system' suggests that it is interconnected and organised – two things of which our mental health system is far from. It is this fragmented, futile system that continues to fail people like my father, my mother, my brother and I.

Since my childhood our family has been touched by suicide in other ways, the most tragic time being the loss of my brother's best friend at the age of 20. It is for this reason, along with my studies in social work that I have become my father's primary carer, as my brother has difficulty understanding mental illness and still holds of lot of anger towards his friend for taking his own life.

As a young primary carer I have been excluded and over-looked by the system, despite my father vehemently requesting my involvement often.

The main issues that I believe need change are:

- **No mental health care service has ever made an effort to involve me in my father's care. My experience as a young carer in the mental health care system has been terrible.** I have cared for a parent who has been diagnosed as bi-polar for about 10 years, which includes 4 lengthy hospitalisations, 2 stays at PARC and repeated communication with the CATT. I am yet to be involved in a treatment meeting or called by any mental health professional involved in my father's care – despite me calling often and both myself

and my father requesting I am included in meetings and communication regarding his treatment. I am officially listed as his next of kin, nominated person and mentioned on his advanced statement, even though I don't live with him. I was first involved with hospitalisation at the age of 20, nobody called me or notified me that my father was in the mental care unit at ██████████ Hospital. I now know he had been taken in in the middle of the night by police after making threats to murder his boss – he was paranoid and delusional. I was unaware that he was in there for more than two days. During this time I was searching for him and receiving strange calls from him as he was delusional. When I tried to ask the hospital if he was there, they told me due to privacy reasons they could not say. I WAS HIS NEXT OF KIN.

He had been asking for me for days, the nurses told him they would call, but they never did. Throughout this 6 week hospital admission there was no outreach from the hospital to me at all. I was never notified of any meetings with doctors or social workers. I did manage to set up a meeting with the social worker so that I could understand what was happening and how I could help, but he was discharged before it was held so they cancelled it.

- **We need better community education and awareness programs around severe mental illness.**

There needs to be a lot more awareness at all levels of our community about acute mental illness. Awareness initiatives such as “R U OK?” day has been great in reducing the stigma in high prevalence, yet low level mental health issues, but there is still a lot of stigma impacting the 3% of Victorian’s that have a severe mental illness. That stigma not only impacts those 3%, but their families too. My father removed himself completely from our local community after someone in a leadership position told him he was “crazy” and should go “pop a few more pills to get right in the head”. This may have been a passing comment to some, but for my family it meant the community connections and the family relationships that hinged on these connections, disintegrated in an instant. My father went from supporting my brother playing footy every week, to not being able to even drive through that suburb. This last several years and my father and brother’s relationship has never been the same again.

- **There needs to be far better training and understanding by and mental health care workers about how mental illness impacts families, particularly children.** All workers within the mental health system should be educated around how mental illness impacts family, particularly children, including those from non-nuclear families. This way there are multiple points of identification and intervention (though this requires family inclusive services to be readily available and accessible).

- **Accessible and appropriate family supports are needed.** After my father’s 4th hospitalisation that I was involved with, I was offered some support from MIND carers but when I looked into it – there was nothing for me, as a young carer in her early 20’s. Everything was framed around older parents caring for their children or FaPMI, which was supporting young kids with play groups etc. I felt lost and alone. It has only been since finding Tandem that I feel heard and validated as a carer for the very first time, but sadly I only discovered them 2 years go. We need to support organisations like this so they can flourish and support more of our community.

- **CATs need to be upskilled in supporting family’s and carers, as well as have drastically increased resources.** In my experience CATS are generally unresponsive when you most need them. Despite my calling them when my father had a serious episode of self-harming, they wouldn’t come to see him, saying that it “didn’t sound serious enough”. When I continued to call them as the situation had become an emergency, they never got back to me. I was left for hours without a call back in the house with my dad who was cutting himself with a butcher’s knife. They told me to call the police but when unwell my

father often threatens to suicide by the police if I call them. I was 20 and I didn't know what to do when the CATT wouldn't help. Now, I have just stopped calling them. I have never had a good experience with them. **When family call CATTs they should refer family and carers on to support services too.**

- **There needs to be a re-appraisal of the current mental health care priorities – we need continuity of care that prioritises the persons recovery – over cost, over freeing up a bed.** At the moment, there seems to be no emphasis on long term follow up and planning. Waiting lists for further treatment after the initial diagnosis and or hospitalisation are very long. Following a significant hospitalisation and stay at PARC my father was referred as a high priority for community support, he waited 22 months for further treatment follow up! This is simply unacceptable.
- **NDIS is a step backwards for our mental health care system – it is deficit focused and does not support the person's wider ecosystem and their family.** It was simply not set up with mental health patients in mind. It is very hard to access and navigate. The NDIS is not all bad though – it has allowed my father to set up a network of support and to be able to see his psychologist every two weeks. The result has been huge, he has entered the peer workforce 4 days a week and has had no major episodes. However, he had to go through a lengthy appeal process to be accepted, which took a toll on his mental and physical health. Now having been doing so well, he recently had a review which halved his funding. It seems that the NDIS has seen how well he is doing and assumed he no longer needs support – without recognising that is BECAUSE of the supports provided by the NDIS that he is the way he is now.

Overall I think that the system needs to be restructured, so that it prioritises recovery and recognises family, community and our social connections as central to that recovery journey.