2019 Submission - Royal Commission into Victoria's Mental Health System

SUB.0002.0004.0008

Name

[redacted]

What are your suggestions to improve the Victorian communitys understanding of mental illness and reduce stigma and discrimination?

"Education through talks, TV programs, articles in papers/magazines and leaflets to bring it out into the open, some education about different illnesses, helping people to become aware that anyone can be affected, that many people suffering a mental illness are very lonely and having an organisation or venue to foster making friends could help a lot."

What is already working well and what can be done better to prevent mental illness and to support people to get early treatment and support?

" At this point people are not experiencing good mental health, they are experiencing mental illness. Positive, empathetic,encouraging and supportive engagement with mental health workers, especially at the beginning of a journey in mental illness, is very important. Again, education especially around helping people to ask for help and realising that it is another illness, not a shame. Having people in the community e.g. GPs, police, teachers, community members who, if they suspect someone is struggling, can provide encouraging and positive links to assistance."

What is already working well and what can be done better to prevent suicide?

Improving continuity of care in staff would help build more positive relationships and trust.

What makes it hard for people to experience good mental health and what can be done to improve this? This may include how people find, access and experience mental health treatment and support and how services link with each other.

"The pressures and demands of life these days, and opportunities to learn ways of dealing with the issues that affect our lives. It must take a lot of self motivation and determination to set out looking for assistance with mental illness; there needs to be more information in the public eye, first point of contact details, and strong links between organisations."

What are the drivers behind some communities in Victoria experiencing poorer mental health outcomes and what needs to be done to address this?

"Alcohol, drugs, music festivals. Perhaps a lack of work opportunities, lack of activities or studies to engage people and prevent having nothing to do but 'console' themselves, or find ways of trying to escape their lives."

What are the needs of family members and carers and what can be done better to support them?

"Family members need to be acknowledged as such, included as such, educated about the relevant illness, and educated as to how to best deal with different situations. Referrals to support groups is very helpful. Families and carers need to be listened to."

What can be done to attract, retain and better support the mental health workforce, including peer support workers?

"Employing more staff to reduce the current pressures; nursing staff who are just that, caring people who actively care and give time to patients, rather than being pressured to do paperwork, see the prescribed number of people etc, Improve safety and job satisfaction. I believe that if there was a significant focus on services to improve quality of life for people in the community, such as a number of varied activities and crafts, varied forms of exercise, counselling, psychotherapy and behavioural therapy where appropriate, people would be happier, have something to get up for in the morning and therefore be more mentally 'well'. There might even be fewer hospitalisations and more time for staff to engage positively with patients. I have written on this in my attached document - I know it would not cure schizophrenia, but I do believe it would have helped my son significantly and given him a better quality of life. "

What are the opportunities in the Victorian community for people living with mental illness to improve their social and economic participation, and what needs to be done to realise these opportunities?

"I think there are some opportunities out there but they are not advertised or promoted very actively by key people working with people with a mental illness. This ties in with my reference to quality of life. There needs to be a much stronger focus on any services which would improve quality of life, and sense of self worth. Opportunities for employment or volunteer roles should be increased and actively promoted."

Thinking about what Victorias mental health system should ideally look like, tell us what areas and reform ideas you would like the Royal Commission to prioritise for change?

"For acute or emergency admissions - more beds, so that beds are available, and so that people are not discharged too early because someone else is worse off and needs a bed more . On discharge from acute admissions - more dedicated staff/services to engage with and support people in the community in an engaging, supportive and empathetic manner. Accommodation - there is a huge need for lots of more appropriate housing in the community, as well as housing overseen by staff. More dedicated staff in both acute and community to remove the pressure and enable them to spend more time and really engage with people, thus creating more positive relationships and trust. More focus on appropriate services to enable people to deal with their lives - behavioural therapy, education on how to recognise when one is becoming unwell and the steps to take, and places to go; counselling, psychotherapy etc. where appropriate. More focus on services to improve the quality of life - various exercise, activity, craft, friendship etc. services. "

What can be done now to prepare for changes to Victorias mental health system and support improvements to last?

Take on board all feedback and act to implement change as soon as possible.

Is there anything else you would like to share with the Royal Commission?

"My story of my son's journey over 16 years - he is not longer with us, all this is too late for him, but there are still thousands out there struggling, and I would hope that I could play some little part in bringing about change. Over those years there have been so many times when I felt no-one really listened, I was not heard, despite letters to a Clinic Manager, the Complaints Commissioner, the Premier, and the Minister of Health (it was nearly a year before this letter was answered). Most of the time I felt totally alone, apart from a small support group in a neighbouring town - this group was like a lifeline to me. I suffer the grief of the loss of my son, a loved family member and a person of worth. Even worse is the grief I carry at what he suffered over 16 years, not only from a terrible illness, schizophrenia, but also in the mental health system."

AN APPEAL TO THE GOVERNMENT FOR CHANGE AND MORE FUNDING FOR MENTAL HEALTH SERVICES
OR

PEOPLE SUFFER NOT ONLY A TERRIBLE ILLNESS – BUT THE MENTAL HEALTH SYSTEM AS WELL

My son once said *"It's not a Mental Health System Mom, it's a Mental Illness System – and it is ill itself"*
Some truth in that?

Here is something that is NOT WORKING – WHY NOT CHANGE THE SYSTEM?

Under the current mental health regime [redacted] was worse off, our family is worse off, and the mental health system is worse of, given what the last 16 years must have cost, especially in hospitalisations – nobody has gained anything at all.

The last sixteen years of my son's life were filled with suffering – suffering one of the most horrible illnesses, schizophrenia - and at the same time suffering the current Mental Health System.

Through these years there were some times when he played a negative part in his journey, often **because** he was ill; and there were times when he desperately tried to manage his life.
From the beginning there was **very little** opportunity for him to build up **trust in staff due to constant changes**, or in his treatment, and **no time for staff to get to know him as an individual**, not as just one of the many in the 'passing parade' of clients, with the **main focus on medication**. **There is lack of adequate staff, lack of time, in some cases lack of ability, lack of a positive living environment, lack of activities, lack of holistic, positive and more supportive treatments – due to a LACK OF FUNDING, and THE ALLOCATION OF CURRENT FUNDING**.

Mental illness is said to be hugely on the increase in one form or another. Add to that the problems arising from ICE at the present time. If nothing **significan**t is done to improve mental health services very soon, the crisis can only worsen, and it is already bad enough.

I believe my son suffered all the contributing factors to schizophrenia:
- a number of **really traumatic events** between pre-school age and university, and I question whether he received the appropriate help or counselling
- **stress** – social, emotional, financial, and study stress while at university
- possibly **a predisposition to mental illness**
- some **use of marijuana**, first socially, then to 'cope' with the stresses
- attending a festival where there were **drug**s around

[redacted] journey into hell started in 2001 at [redacted] a New Year's festival, where he was given a 'spaceball' which tipped him over the edge and he experienced his first psychotic episode. **Festivals such as [redacted] and other music festivals continue and more victims and families continue to be subject to the consequences of what so often happens there . . . .**

It is **impossible** to get across the reality and extent of the suffering, anxiety, difficulty and frustration of the last sixteen years, but in brief some of the things [redacted] and his family, endured include –

- 23 hospitalisations over 16 years, a few of those for periods of 1-3 months, in ACT, NSW, SA and VIC
- Privacy issues, when we were sometimes given no information as to how [redacted] was, and **no guidance** as to how to deal with the situation
- [redacted] inability to complete studies due to illness and hospitalisations
- Many unpleasant side effects of the medication, such as feeling 'like of zombie', unable to function properly, disrupted sleep, lack of motivation, huge weight gain, a loss of self confidence and self esteem, loss of independence
- Unexpected discharges from hospital while **clearly still unwell**
- Really upsetting phone call between myself and a psychiatrist when I questioned why [redacted] was being discharged when **obviously psychotic** - extremely abrupt, rude and unsympathetic , saying 'he can't stay here forever'
- A discharge when the staff could not tell me where he had been discharged to; the case manager phoned and asked me if I knew where he was.....
- When I (in NE Victoria) received a call from [redacted] (in Melbourne) one night, extremely distressed, saying he had to gas himself as he could not continue and hung up; I phoned the Crisis Team in Melbourne and was told they were **too busy to check on him – IF** they had time they would **try** to call on him **some time the next afternoon**
- Two **positive** things he got involved in were **Outdoors Inc.** and the **Community Kitchen** – till **FUNDING WAS CUT** and they ceased to operate
- He also received a grant to set up a community garden at the public housing flats where he lived, giving him **something positive to think about and do**

- Admissions to hospital very difficult, particularly where police where involved – some police were very good, others dreadful; if a family member initiated the admission it often resulted in very strained relationships with [redacted] who understandably felt let down/betrayed by us, and we often did not hear from him for ages, leaving us worried and anxious about him
- Extreme loneliness, sadness, depression, difficulty in making new friends, lack of activities, lack of opportunity for employment, lack of trust, loss of confidence and self esteem
- Handling of his finances given to State Trustees – while practical and necessary, it added to his feeling inadequate, with a sense of losing his rights etc
- When [redacted] became unwell while in Tasmania visiting his father, my daughters and I had to deal with the situation as the current case manager was so **slow, dithering around as how to deal with the situation** – my eldest daughter flew over and brought [redacted] back to Melbourne.
- After discharge from hospital, staff came to [redacted] flat each day around midday for 12 months to administer his meds, which bombed him out for the rest of the day; he ended up being awake all night, going back to bed in the morning, only to be woken around midday for the next dose of medication. This was a particularly bad year, with [redacted] **frustration and anger at the system building up.** When we requested that the meds be given in late afternoon or evening we were told they could not do that as there was **not enough time and they could not pay overtime**.
- During this time the staff apparently had a form to fill in relating to their visit, one of the questions being "**Do you feel suicidal today**?" This not only infuriated [redacted] but was also extremely depressing, especially when it happened almost every day, very often from another 'stranger' (case workers constantly changed).
- After one of [redacted] visits to me, the case manager told me I was 'untrustworthy' as **I** had not administered [redacted] meds.
- The public housing flats where [redacted] lived for the last 8 years was the most **depressing and negative place one could find, especially for vulnerable people.** The place was riddled with rats and mice, almost everyone living there probably has problems with alcohol, drugs or mental illness; the police often called at night when there was some disturbance or violence going on.
- During one of my visits [redacted] neighbour came to his front door, aggressive and abusive and I was quite frightened. When I wanted to phone the police [redacted] said not to, as it would be worse when I left – **what a way for vulnerable people to live**.
- During **the last eight years case managers were constantly changing**, so **little continuity of care**, or chance for them to get to know much about him, or for him to build up trust in staff
- I was **never once able to make an appointment with the psychiatrist** – who only saw [redacted] **twice a year**.
- The **doctors changed every three months** so there was also **no continuity of care** there either, with [redacted] having to constantly be dealing with yet another stranger.
- On more than one occasion, **because the psychiatrist was away,** action could not be taken e.g. having his care transferred to where he was staying with my daughter because he was afraid to go home to his flat; he was having his injections where she lived and **they were very concerned about him** and felt they should be monitoring him, but the psychiatrist was away so his case could not be transferred so - **he was not monitored**
- Similarly, when the family finally arranged accommodation outside of Melbourne to a better living environment and requested the transfer of his care to that area, **nothing could be done for some weeks until the psychiatrist returned from wherever he was**. I took it upon myself to contact the local mental health services in the North East and informed them that he would be coming, that I was not confident they would receive the relevant paperwork in time, and gave them what information I could
- [redacted] was switched from one heavy medication to another a number of times, with long periods in between when we do not believe the effects, or lack thereof, were adequately monitored
- I question the amount of information passed from one service to another; I was sometimes asked what medication he was on, or what dose he was on, I was also questioned about his history
- [redacted] was given a copy of an assessment to have him put back on a CTO, at a time when he was very low. In it was a statement saying that they did not expect to see any improvement in his condition within the next twelve months – not exactly something positive for him to read at that time

[redacted] finally moved into his new home in North East Victoria in mid March 2016, so very happy to be there. We felt this was the beginning of a much better chapter with 100% improved living conditions and environment; and, while still having the same problems, the mental health team is much smaller and more personal, with the promise of more continuity of care.
We knew that he was quite depressed, and really unwell despite the injections which were doing **absolutely nothing** to help him.

After phoning 000 around midnight one Thursday and telling ambulance staff that he thought he was going to hurt himself, [redacted] was taken to the Emergency Dept. and then discharged from Emergency Dept. at **2.30am and walked home alone.** Next morning he phoned and asked if he could come to me for the week-end. We struggled through the week-end, and he was admitted to hospital (via a local GP) on the Monday because he was suicidal.

I now believe that by the time [redacted] got to his new home in [redacted] he was actually more unwell than I realised, and suffering far worse depression than he let on. He tried to hide things as he was always afraid of being given more medication with horrible side effects, and he did not want "to be a burden" to us.

By this time he had no trust in any mental health staff, hated having injections which were doing nothing for him anyway, and had an overwhelming sense of fear about everything – staff, treatment, how he could continue, even mistrusting of family at times. He desperately wanted a job but could see no way of getting one, he was afraid of the future, he told me he felt he was a burden to everyone, that no-one understood what his life was like.
He also asked me to take him shopping once a week as he was afraid to walk to the supermarket as he felt as though he was going to collapse, that he felt he had no strength or energy.....

[redacted] spent two nights with me in August and when I returned from a walk on the [redacted] [redacted], I found the police waiting for me at home with the news that [redacted] had died in a head on collision just out of town, along with the driver of the other car, both cars written off ....

We are all struggling to come to terms with the culmination of the 16 years of struggle - our devastating loss, the terrible journey [redacted] had to endure, and the overwhelming sadness that he did not get to enjoy what I think could have been a somewhat better chapter for him.

Why, and how, did this happen?
With no witnesses to the actual collision, we are just left with questions. The eventual conclusion of the investigation was that
 * the possibility of a blackout or seizure could not be ruled out due to a medical condition he had, and which were also side effects of the heavy medication he was prescribed;
 *neither could [redacted] mental state be ruled out.

We, his family, have to live, not only with the loss of our loved one, and a person of worth;
- we have to live with the questions around what happened on that day;
- we wonder whether he had a blackout or seizure (which he had had in the past)
- we wonder whether there was something else going on physically for him, as he had told me on more than one occasion that he felt he was going to collapse
- we also have to acknowledge that it *may* have been suicide on [redacted] part because of his **low quality of life**

AND we have to live with the fact that another person died along with [redacted] and his family is also grieving their loss.

I can understand that he may have had a plan, perhaps to drive into a tree?
But I find it very hard to believe that he would have deliberately driven into an oncoming car with someone in it. I also believe that he would be devastated to know that another person also died in the collision.

But we have to live with it all............

[redacted] was not only a loved son and brother, he was very intelligent and a thinking person, he had a great sense of humour, a beautiful singing voice, could turn his hand to things practical, was patient and kind to the elderly and kids, and had a great concern for the environment – what a loss of an essentially good human being .....

I think of the many hundreds who endure what [redacted] did, many with no family support, they are completely alone. **It has to change.**

THE LOW QUALITY OF LIFE is the issue I would like to address in regard to the **Mental Health Services**.

I feel that, from the client's perspective, there needs to be a **real change of <u>focus</u> from medication and psychiatrists** to **services to improve the <u>quality of life.</u>** I really believe this would have made a huge difference to my son's life – and could do so for the many hundreds who are still out there really struggling. I am sure that most of us know only too well that if there are no positive or enjoyable things happening in our lives, we can be left feeling low, that there is not much quality in our lives and no reason to get up in the morning.
How much more so in the case of vulnerable people suffering a mental illness of one sort or another?

Thinking of my experience alongside my son, [redacted] I saw that for him the main focus in his life for most of the time was on medication of one sort or another, and psychiatrists; once those aspects were dealt with, he was mostly left to live as best he could; of course there was the passing parade of 'case managers', in Melbourne that being very much the case of yet another stranger to engage with as they changed so often.
There was **no continuity of care** – for the last eight years the **psychiatrist saw [redacted] twice a year**, the **doctor changed every three months**, and **goodness knows just how often the case managers changed**. I venture to say that I don't think there was anyone in the system who got to know [redacted] **the person** – merely [redacted] **the case**, and even that not so well, over his sixteen year journey in the Mental Health System.

There were a few things which did improve his quality of life, and which he very much enjoyed – and he was happier and in a far better mental state when he was involved with these things. They were :-
*Outdoors Inc – **until funding was cut**
*The Community Kitchen, **until that ceased**

*A photographic course at Prahran Mission, with him winning a prize for one of his pictures at some stage

While medication may be necessary, I really believe that the **main focus should be on quality of life, and services to improve the quality of life**, which would result in a happier, more 'well' person, and perhaps even less hospital admissions.
In so many instances these people end up sitting smoking, drinking coffee, desperately lonely and with nothing constructive or enjoyable to occupy some time in their day.
Loss of motivation and self esteem are also big issues when people are unwell, and it is very hard for them to initiate things for themselves.

I believe that if there was much more attention given to
*getting to know the **person**, **not the case**
*engaging people in **positive and enjoyable** activities such as
*walking groups, meeting up for coffee, an exercise group, yoga, thai chi, or chi gong
* perhaps swimming or tennis
* mindfulness
*community kitchens
*organisations such as Outdoors Inc.
* cultivating hobbies such as woodwork, gardening, art of all sorts etc.
*where and when appropriate, counselling, behavioural therapy, psychotherapy
*guidance in learning to identify the signs of becoming unwell
*learning to manage symptoms where possible
* **more positive accommodation and living environments** – at present people are put into the most depressing places, surrounded by many others who also have mental health issues and drug or alcohol issues.....
.......the result would be a better quality of life and therefore a more 'well' person.

I feel this would have greatly improved [redacted] attitude towards his treatment teams and his treatment, his co-operation, as well as his quality of life.

Balance the **cost and outcome** of such treatment with the current one which usually includes numerous very costly admissions to hospital ......
How would this weigh up in time, money and in human suffering?
I accept that it may not always be easy to engage people in these activities – but, as in my son's case, I do believe there are many periods when people are doing 'well' when there could be positive connections made, both with activities and with staff.

Over these 16 years of our journey I have come to know and understand that Schizophrenia is not easy to deal with or to treat, as is also the case with many other mental health illnesses. I say **our** journey, as [redacted] had a family who tried to support and encourage him, with little information, support or encouragement from the Mental Health Services. **He became ill at 25 so missed all the focus on early intervention**. [redacted] was an adult, but he had no wife or partner to be beside him, so I tried to do that, but was very often shut out, especially in the early days.
I have also come to see and understand that Mental Health is a challenging, difficult, and I would think exhausting, area to work in, with much still to be learned.
I believe that it is an area of health that is rapidly increasing; the system is already in crisis, how much worse is it going to get? For staff and for clients....

In our world today things that are working quite well are often changed, just for the sake of changing.
What we currently have is **not** working – **WE NEED IT TO CHANGE.**

It would be interesting to know what [redacted] treatment over 16 years has cost the government – **and no one has gained anything, the people who did do their best have achieved nothing, and [redacted] had no quality of life, and he is no longer with us now.**

Equally interesting would be the result of the alternative approach I am suggesting – perhaps the workers would be rewarded with a happier, more peaceful, more co-operative, and more 'well' client, and perhaps [redacted] would still be alive?
It is too late for [redacted] it is too late for us, but ......

Here is something that is NOT working - WHY NOT CHANGE THE SYSTEM?

Given that all that I have written here is a summary only, I can only trust and hope that it will be really understood when I say that

"I suffer the grief of the loss on a son, a loved family member and a person of worth –
Even worse is the grief
of what he had to endure through his illness, and the Mental Health System over 16 years."

Admission Summary

1st Admission	**Jan 2001**	[redacted]- sunburn, dehydration, catatonic after [redacted] a music festival. I was told he was lucky to survive this incident.
2nd Admission	**May 2001**	[redacted] – Hospital could not tell me where he was discharged to, his case manager phoned to ask me if I knew where he was. It was [redacted] himself who phoned to say he'd been discharged and tell me where he was staying.
3rd Admission	**Apr 2002**	[redacted]- Tried to find alternative treatment
4th Admission	**Oct 2002**	[redacted]- After discharge I advised [redacted] against going to Confest again. I don't think he got there, but ended up in hospital again in
5th Admission	**Dec 23 2002–Jan 2003**	[redacted]– Not much input, always privacy issues raised
6th Admission	**Jan 21 2003–Feb 2003**	[redacted] No information
7th Admission	**May 2003**	[redacted] – Very little input from them to me
8th Admission	**Jun/July 2003**	[redacted] –
	Aug/Sep 2003	After discharge [redacted] very unwell, very upsetting at his sister's in [redacted] after discharge, then showed up in [redacted] having driven from [redacted] shaking so much he could not hold a cup; tried to get help from [redacted] but came home from work one day and [redacted] was gone.
	Nov 2003	No one had heard from [redacted] for about two months so I went to the police who found he'd been seen in [redacted] SA, "either suffering mental illness, or under the influence of drugs".
9th Admission	**Nov 2003/Mar2004**	[redacted]– Probably his longest stay in hospital. Police in [redacted] arranged for airlift to [redacted] hospital where he spent approx 3 months. Prior to discharge to [redacted] some brain tests were run and in a video conference we were told [redacted] was very fortunate, that there had been little damage to his brain; if in future he chose to go back to study, or take up a job he would be quite capable. I wonder whether this information was ever passed on? **I question the amount of medical history passed from one hospital to the other, suspect it is just basic. More than once I was asked what medication he took, what dose he was on etc, yet I was often told nothing.**
	Mar 2004	Care transferred to [redacted] [redacted] was to stay with me till we found suitable accommodation, but not long after he arrived he became increasing unwell, locked the case manager out of the house, would not talk to me etc. etc. Very traumatic this time getting him admitted.
10th Admission	**May/June 2004**	[redacted]- Absconded from [redacted] found in [redacted] at [redacted] by police and taken to **The** [redacted] overnight, then transferred back to [redacted] [redacted] **On discharge from [redacted] was clearly very unwell – I had a very distressing phone call with the psychiatrist when I queried why he was being discharged. I wrote a letter of complaint.**

	Sep 2004	No contact from [redacted] till his call to a sister for her birthday.
	Dec/Jan 2004	I received a couple of very brief, curt/angry calls, but had no idea where [redacted] was staying. He always struggled to deal with the fact that I had him admitted, felt he had been betrayed etc.
11th Admission	**Apr 2005**	[redacted]– I did not even know he had been admitted there till he called one day to say he was being moved to
12th Admission	**Apr 2005**	[redacted] – Question of trialling Clozapine raised
13th Admission	**Jun/July 2005**	[redacted]
14th Admission	**Nov/Dec 2005**	[redacted] – question of Clozapine raised again
15th Admission	**Aug 2006**	[redacted]
16th Admission	**Oct 2006**	[redacted]- Clozapine on agenda again, also considering trying ECT
	Dec 2006	Moved into [redacted]
17th Admission	**Jan 2007**	[redacted]
	Jan 2008	On 650mg Clozapine, considering Abilify as well to perhaps help with some side effects eg weight gain etc.
	Oct 2008	Moved into flat in [redacted], arranged by [redacted] A few months later I was advised that it had come to light that [redacted] was not in their area so his care had been transferred to [redacted]. **I was upset at this, as the services under [redacted] seemed to have been a bit better, albeit not without issues. The psychiatrist was extremely helpful, the best, most caring and down to earth, I had encountered on this journey.**
18th Admission	**Aug 2010**	[redacted]
	Sep 10-30th 2010	Discharged from [redacted] to [redacted] while social worker helped with tidying and cleaning up the flat. **Had there been occasional home visits, staff would have seen that [redacted] was not coping with that aspect of his life.**
19th Admission	**Dec 2nd 2012**	[redacted] His sister brought him back from Tasmania where he had gone to spend his birthday with his father. (He became unwell, Dad said he had to move out and go to backpackers, rest of us became worried when he did not respond to texts or phone calls.) [redacted] basically 'bombed him out' as they didn't use Clozapine, until a bed became available at [redacted], his treating hospital.
20th Admission	**Dec 4-2012 to end Jan 2013**	[redacted] for 5-6 weeks, then **transferred to** [redacted] while arrangements were made to get flat cleaned up – really dirty, and packed with goods. I stayed with my daughter in [redacted] for a week, travelling into Melbourne every day (3 hours on the train) to spend each day working with [redacted] to try to get the flat cleaned up. **[redacted] had been doing extremely well just prior to this admission, clinic said they thought of him as one of their 'success stories', State Trustees had handed back his finances for him to take charge of, he had researched and booked his holiday in Tasmania himself to spend his birthday with his father, and he also planned and budgeted himself for a week at the coast with his family over Christmas.** After this discharge **staff called around midday every day to give him his medication which knocked him out for the rest of the day; he was then awake most of the night, had the morning to do things before more meds at midday again. Towards the end of the year they gradually got him to self medicate for one day per week, then two days per week, and so on. During this time there were extremely varied spaces between him having his meds and it took the whole of the year before he was self medicating and taking meds at night again - an extremely difficult year.**

From here on [redacted] struggled through life, with medication issues, no continuity in care as staff were always changing, and no time to build up trust, but also with some relatively good patches. The family took him to Paynesville for his 40th birthday where we were accommodated between a cabin and a moored yacht which he particularly enjoyed – so much so that he arranged to have another spell there on his own, all booked and managed by himself.

21st Admission	**Sept 21st 2015**	[redacted] Family trying to make_contact since13th, [redacted] did not keep appointment with case manager, not at his flat, did not show up at the boat in Paynesville where he was to spend another 10 days; the family did not know where [redacted] was for about 10days and really worried until I got a call on 25th Sept advising he was in [redacted] where he'd been admitted on **21st** after being picked up by police outside hotel in [redacted] 'behaving strangely'. He spent **7 weeks there waiting for a bed in** [redacted] **his treating hospital – NO BEDS.** Then he was discharged very suddenly while **clearly very unwell** back to flat which was in appalling state.

22nd Admission Approx mid Nov [redacted] –

On transfer from [redacted] it was decided that his treatment would change from Clozapine injection to tablets as by [redacted] now had a history of non-compliance; this is quite common as the medication has bad side effects and makes clients feel so terrible, or when it is working, they feel better and think they no longer need to take the tablets. He was put on an injection of paliperidone.

After discharge my daughter tried to go in at week-ends to help him clean up his flat, spend time with him etc. Really unwell and then at some stage asked if he could stay at her place in [redacted] as he was afraid to go back to his flat – he said he was being abused, threatened etc. He came up to [redacted] for Christmas, very thought disordered and afraid to go back to his flat. **Between Jan and March 2016** he stayed either with my daughter in [redacted] or myself in [redacted] as he refused to go back to his flat because he was afraid of being abused there.

Over some time I wrote letters to the Premier of Victoria, the Minister for Mental Health (it was not far off a year before I received a reply to the first letter!), the Complaints Commissioner – I was left feeling nothing would be done, that there was no one who really 'heard' or took anything on board, it felt like coming up again a brick wall.

My son's living conditions were appalling, we were not happy with his treatment, case managers were constantly changing, there was no continuity of care, the psychiatrist saw [redacted] twice a year, and in the approximately eight years that [redacted] was under the care of [redacted], never once was I able make an appointment, to meet, or speak on the phone with the psychiatrist – he was too busy. The best we had towards the end was a teleconference with my eldest daughter, myself, the Centre manager and the psychiatrist, a while before we decided to move him out of the city.
We started looking for a place for him to live, and arranging a transfer from [redacted] services to [redacted] [redacted] This meant he would be closer to me, it was an area he knew, far more peaceful and less stressful than where he was in Melbourne, and the mental health service, while still having the same problems, was at least smaller and more personal, and with staff staying in their jobs for longer.

While my son stayed in [redacted] with my daughter, one of the better [redacted] cash managers arranged for him to have his injections there. The clinic in Corio were <u>**very concerned about him**</u> **and tried to have his full care transferred to them so they could monitor him, but <u>nothing could be done as the psychiatrist was away for 3 weeks</u>.**
During one of [redacted] says with me, he took himself up to the local surgery as he said he 'really needed help'. On their referral, I took him to [redacted], we spent approx 3 hours there with various people talking with him, and then he was sent home with me again.

March 14th 2016 - Left [redacted] and moved to [redacted]
No idea why [redacted] was still being injected with paliperidone – all it is did was stress him and it did **nothing** to clear his mind, had been on it for approx. 6 months.
I made an appointment to see the community psychiatrist and case manager on **Thurs 2 June** – my daughter drove up from [redacted] for the day to join us, and my youngest daughter in [redacted]. took part by phone. I found this to be a positive meeting and we felt that there was a chance for his care to be much better than in [redacted] also, [redacted] would be **seen by the psychiatrist a lot more than twice a year, as was the case under** [redacted].
At some point they changed his medication to an injection of zuclopenthixol.

I think it was on **26th May** at midnight that I received a phone call from [redacted]. to say [redacted] had called an ambulance and told paramedics he thought he was going to hurt himself. He spent a couple of hours there, I rang at **3am** to find out what had happened and was told he had been **discharged and walked home on his own**; he had refused the taxi offered.
Next morning [redacted] phoned me and asked if he could stay with me for the week-end as he felt 'safe' here.
That night (**27th**) was dreadful – he called me from his bedroom, sobbing, ranting and raving, terrified of everything, freezing cold, and quite beside himself. I have never seen a person so distressed. I did not want to call an ambulance as I knew that would make him even more distressed. I gave him 3 hot water bottles, more blankets, and took a chair into the room and just sat next to the bed stroking or patting his back for about 3 hours. He eventually quietened and calmed down, thanking me for being there.

We got through Sat and Sun, but [redacted] was very down, struggling with everything, did not want to go for a walk, just sat out the back with coffee and cigarettes, and did not sleep much at night, up and down and in out for more coffee and smokes.
On Monday morning (**30th**) [redacted] went to the local surgery to talk to a doctor about a stone he said he had swallowed when he was in SA and it was blocking his bowel; I was called in and was told he could not go home with me as he was so suicidal – and so to the

23nd Admission [redacted] [redacted] [redacted] [redacted]

[redacted] was really struggling with chaotic thoughts, very depressed and suicidal. Said he felt 'safe' there and seemed quite content and at peace, though very thought disordered. After some weeks it was decided he should go to supported accommodation for a while; they were waiting for a place for him and then suddenly, based on assessment one morning, and [redacted] saying he did not think he needed to go to supported accommodation, he was

[redacted]

I house sat for my daughter in [redacted] from 2nd-7th while she was at conference in UK; called at [redacted] on my way home, he was very down, talked about how lonely he was and gave me a card which I took as a sort of apology for when he was so terrible to me while in [redacted]

[redacted] [redacted] [redacted] - I met with Case Manager to talk about treatment - the zuclopenthixol was also not doing anything to help [redacted] mind, he was also very depressed and lonely. I told her he had asked me to take him to do his shopping as he was scared to walk to the shops as he felt he was going to collapse. The case manager was also not happy about the situation and we discussed various options to try to improve things for [redacted]

[redacted] [redacted]–[redacted] arrived at my place around 5.30pm, saying he had planned a day trip but has missed the last bus back to [redacted] could he stay the night. As not many buses on a Thursday, and I had a full day, I said he should stay that night also and he could get a bus on Friday. He enjoyed his dinner both nights, was restless during the night as usual

[redacted] [redacted] –[redacted] was relatively bright on Friday morning saying it would be good to go with me to the walking group as it was a nice cool morning. At the last minute he changed his mind, saying he thought he would stay in bed a bit longer. I told him that when I got home we could spend some time together, have lunch and then I would drive him back to his home in [redacted]

I left the house at 8.50am, walked and had cuppa afterwards at the coffee shop with the walking group. When I [redacted] home I found the driveway gate open, the garage open, my car gone, and the police waiting for me with the news that [redacted] had died in a head-on collision just out of town, along with the driver of the other car, my car and the other one both written off . . . .