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

SUB. 0002.0029.0120

Name

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

"Treat mental illness in the same manner as all other illnesses. Treat people early - do not allow the episodes to get out of control. Education through schools/media/community groups/all levels of Government. Only employ people in the field who pass with a high EQ and who have relevant qualifications. Education for practitioners in the sector/police and ambulance - role play, presentations from patients and carers"

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?

"Nothing Listen to the patients and carers/families - they are the experts. Not someone in an office who has never met before, yet makes a life affecting decision based on 30 minute presentation. These patients have complex behaviours and psychotic episodes are cyclical. I have observed that the patient - during psychosis, patients can respond to something novel e.g. new worker for approximately 40 minutes. Beyond that they are unable to sustain the overriding influence of the neo-cortex over the limbic system. They simply don't have capacity. Hence it is very important to allow a lot of time, include friends/family. Particularly keeping the same treatment team long term Use the ""Open dialogue"" system. Work in the home where the patient is in safe, familiar surroundings. Not in an alarming, chaotic ED."

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

Nothing Allow the patient 'at risk' to be seen by the local service area at time of crisis - not be denied help because he is 'out of area. You are not denied treatment at hospital if you break your leg while visiting another area!!

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.

"Dreadful attitude and values of the current system. Not getting early support Unsuitable facilities for rehabilitation ""Open Dialogue"" ""Recovery farms"" A rural setting which is quiet and serine. Where all services are housed together. Using psychology music & art therapy. Growing vegetables - being out doors doing manual labour. Assist with cooking, cleaning, planning as capable. Look at sleep hygiene, diet, gut biome. Patients stay here long term while their brains' recover - maybe 6 months. A happy, nurturing, healing place where they return well, rehabilitated and can participate in society. For patients with drug addiction, this facility would allow services and time for them to gradually withdraw in a safe, nurturing environment - where they stay until they have made a complete recovery. drug addiction is an illness, not a crime. It can affect any of us. ""Recovery farms"" WOULD PREVENT SUICIDE, HOMELESSNESS, REDUCE CRIME, NUMBER OF PRISONERS AND HOSPITAL READMISSIONS + SAVE A HUGE AMOUNT OF

MONEY."

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

Poor quality of local mental health system Too much emphasis on the Dr/hospital/drug model Being discharged while still unwell Not listening to patients and cares/family/friends Lack of support services Lack of housing Lack of employment opportunities Lack of regular public transport

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

"To be recognised as the experts in their loved one's lives. For them to be included, respected and listened to. To be provided with long term, ongoing support. Not - you've had your 6 sessions, goodbye!! Carers use a great deal of their personal time, energy and money in the effort to keep their loved one supported. Provide 'on going' education - in up to the minute research, psychology, respite, practical support the home. Research on the health burden caused by intense stress carers are under would show this support to be very cost effective."

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

"Create a culture of respect, care, understanding and recognition Pay well Have 'good' qualifications/commitment Have shift hours which are beneficial for the workers e.g. 10 hours is too long "

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?

"None, since the service were corporatised and now run as businesses. All the money goes to CEO, PA, fleet cars. No longer services on the ground or in the streets. Services only accessible through NDIS Many people with Mental illness lack the capacity to apply for NDIS - provide special workers to assist them. Maybe on admission, or referral or find them in the streets sleeping rough?"

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?

"""Open Dialogue"" approach - in home, preventative, cost effective, ""Recovery farm"" model Seperate hospital 'intake' for patients - NOT E.D. Receive treatment and support at the earliest opportunity Education of police/ambulance and all mental health staff so problems are recognised and addressed as soon as they arise "

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

"Put the patient - their care and recovery at the centre of your 'raison d'etre' Fund, train and implement ""Open Dialogue"" from existing Mental Health facilities Improve the basic qualifications and aptitude required for new workers Improve the hours/pay for existing workers Conduct a compulsory campaign to educate existing Mental Health workers - including stories from patients and carers and the appalling consequences of their careless, current practises

Aquire facilities and open ""Recovery farms"" Compulsory mental health training for police and ambulance personnel Provide on going support to families/cares "

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

"My family has had an awful time over the last eleven years. We have had a handful of good worker in that time. A summary of some of the horrors: - ""your child's mental illness is because of your bad parenting"" - stated a case worker, in front of him. - too unwell to walk to the car or engage in meeting - Dr and colleague stood back and laughed at us!! - when asking for admission - told ""your are not sick enough"" No services provided - fully psychotic one month later. -when asked for support because suicidal - told you can't be seen here - you have to go back to the other side of the city where you live - suicide attempt (drove car into pole at 100kmh)- 2 hours later -in ED after suicide attempt (taken all meds on hand + written notes) told by OT that he hadn't taken enough to kill himself, go home. Luckily nurse on exit did his obs. - he was in cardiac arrest and in the resus. unit for 8 hours. -hospital refused family any contact or information - because unwell person, with no capacity requested it ~ part of his paranoid delusion. So, they had no history and he got worse!! What happened to commonsense and the patients right to proper care - which cannot be give without including cares/family and friends? -this has all taken a toll on my own health "

Complaint to the Mental Health Complaints Commissioner Concerning my adult child " and Peninsula Health, Mental Health services.

Background

- September 2017 under the care of frequent contact with the family as part of care.
- January 2018 alone in my house. I was overseas. very unwell. The police took him to solve took him to solve the police took him to solve took him to
- As he was causing such a nuisance, took out a restraining order and sent him to
- Because he was unwell, he was too paranoid to stay in his apartment and so was sleeping out on the city streets.
- During this time, he was extremely paranoid and shouted at a person he believed was an undercover cop spying on him. Charges were laid. He should have been taken to hospital, not charged.
- He went to the airport, attempting to travel overseas. The Federal police recognised he was unwell and took him to was admitted. He left as soon as he was made voluntary. He walked around was all night, and went back in the morning and asked to be readmitted.
- He then travelled to the police in the police in the recognised that he was very unwell and took him to hospital. He was in the police in
- On discharge, he was sent to **and** his file to **be and** They followed up his care in the community for 2 weeks until he returned to to live.
- H was told he would get follow up care in the community on his return to
 However when he went to
 services in
 he was told that he did not qualify for their services
- had 2 appointments with the period, psychiatrist in this period.
- He had no support (other than his mother). In September, he felt that he was getting very unwell again and he

approached and asked to be put into He was turned away and told he wasn't unwell enough!

- By November 2018 he had full blown psychosis and hence disengaged from his friends and family
- In January 2019, he was making many, many erratic trips to the airport via the freeway he clocked up over \$200 in tolls. Sometimes he slept at the airport because he felt safe as the federal police were there.
- 2/2/19 I visited at his Unit in He was gaunt. His room was filthy and mouldy; his bed was covered in blood from a recent operation. His car windscreen was covered in bird poo, with his suitcase was on the back seat. He was totally psychotic. He said that he couldn't have anything to do with me; I was dangerous because the communists had taken everything I had ever owned.

Current complaint

- 7/2/19 I rang Triage at **Example 1**. (40 minutes waiting to get through) They said they would decide whether they needed to ring or visit him, and that they would ring me back.
- 11/2/19 Triage have still not rung. I rang again. Triage unable to get on the phone. He was not answering his phone to anybody because he believed it was bugged. Despite my evidence, Triage decided that because they were unable to speak to on the phone, that there was no evidence that he was mentally unwell and they closed the case! I was distraught and disgusted. How is the family, who know their loved one best, just disregarded? Clearly he is not answering his phone because he thinks it is bugged. I was told that as he is not answering his phone, that means that he does not wish to engage with the service. However, does not know who is ringing!! (*That's like asking someone with a broken leg to cross the freeway to the hospital if they really want treatment!!!!*)
- Several neighbours, his best friend, and the real estate agent all contacted Triage many times as they were alarmed by behaviour.
- We called 000 and **Sector** who attended many times and agreed he was very unwell. But, because of the criteria, they are unable to take him to hospital until he deteriorates to the extent that he is in danger of hurting himself or others. (*That is like leaving cancer until it is almost too late, before starting treatment!!*)
- Car broke down on Peninsula Link. He had a blowout. He left the car instead of calling the RACV and headed for the airport. When he returned 2 days later, his car had been broken in to. He called and told the police about the break in and organised the car to be towed to However, he did not notice that the number plates had been stolen, and that the door locks and the spoiler removed!!

- I called the **second** police **second** to let them know about the number plates. He was concerned about **second** and was going to attend with a member of the CAT team. Once again, they were aware that he was very unwell, but not bad enough yet, to take him in to hospital. (*that's like leaving someone with an infection until it gets so bad they hope that the treatment is not too late to save the limb)!!!*
- 13/2
 Best friend rang Triage after seeing who cowered, hid in the laundry and told him "he was too dangerous go away, he can't have anything to do with him".
 I rang the Mental Health Complaints Commissioner
- 14/2 CAT Team still not prepared to visit because he wont answer his phone he is not answering to anyone, because he believes it is bugged. He is just using his phone to send abusive texts to his sibling and myself classic psychotic behaviour.
- 15/2 Rang Triage Spoke to a who said she would call back, but didn't!
- 16/2 I rang again and was told they would take no further action "based on previous presentations". He hasn't been seen by the service since he asked for help in September, so I'm guessing they are referring to January 17 – when they called his psychotic episode – bad behaviour? (*That's like going to the dentist with a toothache and being told that last visit nothing showed on the x-ray so we wont bother seeing you today.*
- 19/2 Rang 000 because neighbour, rang. She was very frightened was yelling and screaming and ranting at communists. I also notified Triage
- 20/2 I had a meeting with I asked him to advocate with triage, on my behalf
- 21/2 neighbour, rang me. I called 000 because in the street ranting and yelling 8.35am. He went back inside and refused to open door to police. 9.02am I rang Triage (on hold for 24 minutes).
 said she would see what she could do, to get CAT team to attend.
 5pm from CAT team rang. not answering his phone. CAT had

attended the premises, but didn't know the code for the gate, so they had left. 9pm rang me, screaming, yelling, crying I called 000.

quiet by the time police arrived and wouldn't answer the door. (The police always ring back)

22/2

• 9am Mental health Complaint's Commissioner rang - advised that they would ring me by the 18th and also, send me a letter.

I updated She said call on Wed if I had not heard from

- 10.40am from from rang me because she had had 3 complaints about from his neighbours. She wants access to his apartment. She arranged to meet with me and the police.
- 1pm I met Helen and 2 police at place. The police assessed him as being ok. They have no psychiatric training, and did not appreciate the typical cycles present in psychosis but agreed he was not well.
- 10.30pm rang. had kicked in the door in Unit 2 (next door).
 Claims his keys were stolen from his pocket. rang the police himself, reporting that someone had kicked the door in a neighbour had witnessed him doing it!
- I rang police,
- 11pm I rang CAT. Left a call back message

23/2

7.30am from rang to say had locked himself out. She was on her way to let him in, and was going to offer to clean his bathroom

 to avoid eviction from upcoming house inspection. She talked about getting council support for him.

He is sleeping all day and prowling all night – the same behaviour as last years psychotic episode.

- 11am rang again because had allegedly punched a hole in the shower screen it was actually the bathroom door. She planned to evict him on the Monday.
- 12pm I rang Triage and answered straight away. She had had a call from She advised that is now under the straight away is he lleft a message for them to call me.
- 7.10pm mate mate rang to tell me had rung and was threatening to bash him because believed brother was spying on him - was afraid for his son who has intellectual disability.
- I was on the train returning from city, with my daughter. I got off at next station and rang police. They said they would organise to meet at place, with the CAT team.
- 8.30pm Sister and I arrived at place at the same time as the police and CAT. Curiously, the 2 CAT members had not recognised when he approached their car, nor when he was ranting and running up the street. The brief they were giving the police was ineffectual, offhand and cursory. The police however had already attended and met me previously they pursued him and we left.
- 9.37pm CAT rang me had been arrested, manhandled and capsicum sprayed. CAT advised me to call ED immediately to inquire about
- I rang ED and was put on hold for 25 minutes. I hung up.
- 10.46pm I called ED again. I was told, very rudely, by the person who answered; that she had no way of knowing that I was who I was saying I was. If I wished to speak to the doctors, I had to come in to the hospital. (It was late, I was exhausted and the hospital is 30 minutes away) She had no compassion and would not let me pass on any information I was concerned, as had had recent abdominal surgery. (*The surgery has*)

since failed, and I believe it was a consequence of the unfortunate force used in his arrest which was preventable had the service seen to him in a timely manner.)

24/2

- 9.40am I had a call from **General** from the Hospital. **General** had absconded during the night while the guard went off to do something else.
- 12.30pm I attended Police Station asking news of We apologised to the officer who had also copped the capsicum spray. The police were not happy that had been left unguarded and hence able to leave as it has taken such an effort to get him into ED they now had to find him again. The Officer got on the phone and he sounded calmer.
- 3.30pm rang. back in ED, speaking with psychiatrist and about to go to

25/2

- 2.30pm I rang to ask how was. The nurse harshly informed me not to ring, or visit or bring clothes. To have no contact with the hospital at request. This is just reinforcing his delusions it was not a good outcome for anyone.
- Sister rang the Hospital from at dinner time and was told was on the ward but she could not be given any information, at request.

26/2

- father rang the ward. He was told was still agitated. They gave him the name of the meds. did not wish to speak with him.
- 1.30pm the Carer support worker from rang she organised an appointment to visit me.

28/2

- Mental Health Complaints Commissioner, **Table** rang. She had spoken to from **the second sec**
- 12.30 Psych Registrar called me. has nominated his new girl friend " as his next of kin. There is to be no contact with family. We must liaise with from now on even though she is unknown to the family

2/3

• ang. still had the same clothes on that he was wearing on admission (8 days ago). He had been sleeping in the same pair of jocks and socks the whole time.

No duty of care. The male nurse that shift supervised his first shower and put him in hospital clothes.

9/3

- Sister had a text from Advising her that he is suing me, and she is to have no further contact with me. She rang the NUM to tell them that he is still very unwell and paranoid.
- I spoke to she had not been to see him all week. He is sending her excessive numbers of text messages rants (which he does when he is psychotic) stating that it is not safe for he to visit the ward it is too dangerous for her to go there.
- I advised her to ring the nurse and give them this update.

10/3

• planned to go Sunday. I texted her – she didn't go because he was angry. She will give him more time

12/3

- Mental Health Complaints Commissioner rang. They will ring ringing
 and ask them to call me and keep me informed, even though
 changed next of kin when he had no capacity. I am to call on Friday if there has been no call or letter (inst. 18th Feb.)
- By this stage, I am having terrifying nightmares every night. I am sad, upset, anxious, worried, disempowered. The family is cut off think of Maslow's Hierarchy of needs.

I am really worried that may never recover this time – he is so very unwell, and it was all preventable!!!

- 9.pm M sent text to say had been screaming at her on the phone. She had hung up on him.
- I rang the hospital. On hold for a long time recorded message said to ring Call Care if not happy with what is happening on the Ward. So I rang Care Call!!
- They will contact and get the Nurse in Charge to call me.
- I received a return call from Care call, and the gentleman recommended that I visit the hospital in person despite having been told I was not too, previously.
- It was such a relief to know that there was an independent person offering support and common sense.

13/3

- Late morning I visited **I visited** . The reception desk is not staffed, so I was unsure what to do or where to go. I followed the signs and took the lift to I didn't want to go near the window in case saw me, as I did not wish to upset him in any way. I asked a person who came through a door next to the ward, what I should do? She took me to an office where I met the NUM for who, coincidentally, was about to was also in attendance. It was a good meeting. I call me. was able to express my concerns, be heard, and was reassured that the family will be informed as part of recovery. The promised to speak with the psychiatrist and call me in few days. had spoken with Mental Health Complaints Commissioner. I felt that I was taken seriously - not dismissed as I was with the CAT team. She assured me that she would organise a social worker and case worker to begin with while he is in <u>He got neither</u>.
- Shortly after I left the hospital, rang. She had spoken to the registrar and was worse. He had sent her a barrage of nasty messages. She requested that his medication be changed, as what he was on was not working. He is unable to visit because he is too angry.

- 14/3 His friend "was expecting to visit today. He was not allowed to see him he is too unwell and now in the HDU Friend "spoke to male nurse.
 - Registrar rang me is worse. He wanted information on previous medication.
 - rang a second time to request I attend a meeting on Mon 18st March, 11.30am.
 - rang a decision has now been made to involve me in care. He is in HDU where there are 2 patients to 1 nurse.. He is more aggressive and paranoid now with some of the other patients and doctors

15/3

- Sister rang. She had been able to get update from the hospital no change in condition. She is worried about the brain damage caused by this episode. She is relieved to again be able to have contact with the hospital
- I rang she is worried is accessing news/YouTube etc. and being overloaded with trouble and strife from around the world. She recognises the thread of news event in the rants and texts she is receiving from at all hours of day and night. "Some very horrible stuff" She feels he should not have his phone but give his brain a rest; perhaps this is instrumental in slowing his recovery?
- I rang **a transform** to give her an update. She had received an email form Sat March 9th <u>while he was in the second</u> wanting to end his lease on March 31st, how much did he owe for damage? He may be interested in another property. She sent me a copy of the email.
- I rang to speak to Doctor or NUM. I got the nurse in charge, She was not listening she asked me 3 times the name of the patient I was enquiring about, she asked me twice what my name was. As I was explaining my concerns, she kept talking over the top of me. I was trying to tell her that is conducting business on his phone from the Ward. He is accessing negative stories and upsetting himself. Could she please remove his phone could the phone use please be limited to 30 minute periods and supervised.
- Her response was that she would have to tell that this was what I had requested. She obviously had no idea of condition I can only imagine how well that went down go on and poke the angry bear with a firestick!! I felt angry at attitude, lack of courtesy, lack of knowledge, lack of empathy should she be in this job? Surely the hospital is liable for what does on his phone they have a duty of care. It is possible he may have bought an airline ticket, applied for a visa, conducted financial transactions etc from the HDU

18/3

- As I arrived at hospital for Drs meeting, I saw and expressed my disappointment at the way I was spoken to by an weekend.
- After a long wait, I went into a meeting room with the Registrar, a young female psychiatrist whose name I did not get. Due to her soft voice and accent, I found her very hard to understand. There was no one there to support me this power differential is unfair. Five times they asked me to agree to clozapine five times I declined. Five times they asked me what my relationship is like with when he is well. Five times I told

them that we get on really well - he is a polite, respectful, funny and smart young man. They explained that **solution** is in HDU because of his paranoia and potential violence.

- I questioned why he had his phone? I explained that he was accessing News/YouTube etc. projecting into his delusions as per texts and rants to Why is he allowed to use his phone screaming and shouting at but no nurses are stopping him. Conducting business from the Ward. I gave them a copy of the email he sent to promised to ring the Agent straight away but he never did. Calls from the agent to the hospital to sort things out were denied on privacy grounds!! (It was going to be tricky for to pack, clean and move his things from the ward!!!)
- I requested that have a social worker as he has so many fines and issues he needs assistance with, to sort out. All a consequence of him being unwell for a ong time with no supports.
- They asked if was a drug user. Not to my knowledge.
- I filled the Drs in on history turned away four times by admission, admission. Denied support on return to admission, admission. Denied support on return to admission of the had been admitted in September when he requested going to all this could have been prevented, I don't understand why they do not have the history from admission. Dr was going to request it. Surely meeting with the family and getting his full history on admission, could have prevented these weeks of getting worse and worse?
- Dr told me that had made so many trips to airport, sometimes sleeping there, as he felt safe knowing the Federal police were there.
- I asked about sleeping pattern they had no idea.
- I requested that his phone be taken away to give his brain a rest sceptical, didn't think it would make much difference. I disagreed.
- Make sure he is sleeping during the night/awake during the day to reset his circadian rhythms. Pacing at night a symptom of his psychosis. Dr thought it was a good idea to check if he was sleeping.
- If he is in solitary confinement with his phone to reinforce his delusions he has no 'reality checks' to bring him back into the real world.
- When said he would check with shout changing the meds I was flabbergasted and reiterated "does not have the capacity" to be making decisions (nor does he have a degree in pharmacology). Clearly what he is on is not working. I evidenced a lack of common sense, an over focus on drugs and no consideration of any other avenues toward recovery.
- I suggested music, massage, someone to talk to he has always responded well to psychology.
- Dr indicated that there was a chance he would not come back they will try other drugs. They were to contact me weekly re progress. But, I never heard from them again.

20/3

from **the provident of the still had no contact from the Drs despite their** promise to me. He is likely to be evicted as his place wont pass an inspection and there have been so many complaints from neighbours, prior to his admission This is an awful strain on me. Is he to be homeless on discharge? How do we clean/pack/move his things?

Afterword: responded to the different meds and once his phone was gone, and his sleep was supervised - he turned the corner in a week. He was never given a caseworker or social worker, despite both being requested

and recommended. He fled to Canberra, because "he was being stalked, his place was bugged and he

was not safe in **Canberra**, because the was being stanked, ins place was bagged and he was not safe in **Canberra** hospital gave him a caseworker immediately. He had psychology every 2 days and was 60% recovered in 3 weeks of their care. He was able to travel to Melbourne for his sister's wedding.

Many thanks, for your invaluable support, encouragement and empathy to me during this distressing period. I am so appreciative and grateful. Kindest regards

Document for the MHRC

Support for Mental Health sufferers/ DSP Financial and Housing

My son recovered from a very serious (preventable) psychotic episode. He got a job for 1 year and one month. And became unwell again. He had saved money toward a house deposit.

Because it was (just) over a year, He was no longer eligible for DSP and had to reapply after a period. However, He did not have the capacity to fulfil the requirements such as Doctors appointments (unable to get out of bed), fill out forms etc. because he was unwell, with no support services.

He was not able to get NewStart because of the money he had saved. So he has had to live on his savings, which are now all, gone.

He has just recovered from a further (preventable) psychotic episode. And has applied for over 50 jobs and is still trying. His rent is over 60% of his DSP – then utilities and food. He has no money for a computer etc.

He is so worried and anxious that if he gets a job and becomes unwell again after a year - he'll end up homeless again. This is not the service our loved one's deserve.

MY recommendation

- The safety net period for DSP should be <u>extended</u> (maybe five years) for people suffering serious mental illness (e.g. schizophrenia)
- Rent should be paid for people suffering severe mental illness. This would alleviate a lot of stress, housing instability and homelessness. (You don't think of paying bills when you are unwell).

