

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

0002.0009.0032

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

"*On a personal note, my son experienced his face being plastered all over the media including Facebook as we sort to find him after he had a psychotic episode and disappeared into the bush. On reflection, this experience added to his stress and embarrassment, however, it opened up the conversation with his family and friends to talk about Mental illness and discuss it honestly and openly and seek to find answers. This helped to reduce stigma and discrimination, particularly around Men's mental health. *More awareness campaigns by the government that Mental Health is a health condition and needs to be treated like any other condition. *More community led talks and discussion on Mental Health - these could be held regularly through the Neighbourhood house network"

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?

"*Sadly my experience is that there is not much working well to prevent mental illness. Both my father and son have succumbed to the ravages of mental illness. It is not known if there was an exact trigger, nor if it was a gene or a disposition. *There is now a much better understanding of treatments, we no longer institutionalize and thank goodness my son has not experienced shock treatment as my father did. However, there is so much more to do. *We need to do much more research on the effects of Gene's, of disposition to Marijuana in youth and the impacts of lifestyle, stress and other medications and their impacts in causing or contributing to Mental illness. *Education in primary schools is needed on the terrible consequences of using illicit drugs *We need to have early access to specialized care. My son at the age of 17 was taken off to the hospital by police to a mental health ward after a major psychotic episode, 4 hours later he was sent home with us with some pills. Yet what he and we needed was education....ongoing support and access to detox and addiction treatments. Sadly we did not receive this and his condition continues, he is now 28. *I have experienced only one outstanding instance of what can be done. My son was sent home from a Mental Health Secure Ward (after being there a week). He was given an ultimatum by the Psychiatrist if he went home - 1 month of no alcohol, he must stay on his medication and if he defied the order, he would be picked up by the police at our request and returned to the ward. That month, although extremely difficult was a turning point. He obeyed the order and has continued to seek the services he needs. *Build more specific Mental Health care facilities - dedicated to supporting people with multiple mental health issues and call these Wellbeing Care Facilities (somewhere that people would want to go) and keep it FREE"

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

"*Having tried several times to end his life, I would say what has worked for our son is a lovely caring family who will not give up on him and who he knows he can go to when in his darkest hours. *What has been invaluable has been our excellent Ambulance services who were

efficient, forward-thinking and caring. Our son overdosed on over 200 prescription tablets and would have been dead in a few hours... the ambulance knew that he would need specialized care and took him to the closest hospital with an ICU. A critical decision. *Our hospitals are amazing, with incredible doctors and nurses who when they see a true attempt at suicide will do all in their power to save that person. I know because they worked on our son for 4 days, cleaning his blood, caring for him with real passion and concern. They though only earn a lousy \$33 per hour. I would pay someone a lot more if my life was in their hands. *Beyond Blue and other services work well, and our son has used them, however, they are under-resourced and really need more money and more good caring people on the other end of the phone *The cost of psychiatrists and psychologists is prohibitive if you are paying as a private patient. My son won't see his psychiatrists regularly - he only goes every 8 months as he just cannot afford the \$350 charged. His psychologist charges \$120. I have had to go with him and pay in some cases to get him to go. How can I prevent him from committing suicide if he can't visit with a professional when he needs them. *Mostly though, a decision to commit suicide is one made by the individual... my father made his decision to take his own life in a hospital. I cannot say if their systems changed because of his death, all I can say is that he made a choice and it is one I have to live with. *Perhaps - this is just putting it out there - try a mental health alarm or call system, which alerts a service that someone is in distress and they need a call or visit. "

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.

" What makes it hard for people to experience good mental health, is the day to day stresses of life. Some of us are able to manage, others are not. Depression, Anxiety is rife. Instead of seeking support (which is often expensive), easier options are alcohol and drugs, exacerbating mental health issues. This occurred with our son after he overdosed on 200 tablets, 1 week later, we were asked by his Doctor if we wanted to take him home, as there were no mental health beds. We decided to, however, there was no support, no detox... just a link to the CATT team. Sadly this was a debacle with the location of our house being on the border of services. We had one visit the day after his return home from a lovely young woman. Then a day later we were told that she could not visit again as we were covered by a different area. That service took another 3 days to contact us and the contact was only by phone... no visit. By this time our son was spiraling out of control again, he then ended up in the bush with ourselves, friends, family, police, helicopters, SES and search and rescue looking for him for 3 days... all these resources, yet all we needed was a detox program and a visit every day from a support worker who could recognize the signs and advise us on what to do. The sector is under-resourced, support workers are overstretched, there are not enough mental health beds, it is difficult to access residential inpatient care unless you have private health insurance. More recently, our son was struggling with addiction, I sought out a public inpatient service. Except you have to turn up at the hospital on a Monday morning only and they only have 2 places (subject to conditions). It is ridiculous... in the end, I stepped in to support him yet again... I moved him home, cleaned up his accounts where he was being chased by debt collectors and took over those responsibilities he could not cope with... all whilst supporting my own parents with palliative and end of life care. He still needs addiction support. To support my own mental health, I have sought out services which although unconventional have kept me sane. These include private insight services ""Teymara"" which both my son and myself visited. This has been an incredible and real support in helping us both find some headspace."

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

"*Having grown up in the Latrobe Valley, at 15 I could access a range of illicit drugs. I did not and never succumbed. I did though see a range of people crippled by drugs. That was 35 years ago. Not much has changed, except the drug, now ICE and Ketamine and plenty of others and hospitals in the area are filled with police guarding offenders who have succumbed. *This low socio economic area is known for poorer mental health outcomes. This could be attributed to something as simple as ""Willpower"" it was much easier for most to say yes to drugs in my younger years that it was for me to say NO. I was teased and ridiculed for my choice. *I now wish that I had the education and knowledge to teach my own child how to build willpower (which is another muscle). That saying NO is much more valuable than being part of the crowd. *Low Socio economic areas generally don't have this knowledge. Building resilience needs to be across the community, particularly in schools and teaching young people the power of NO. "

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

"My main needs as a family member and carer are to take the pressure off me. *Please provide access for my son to good, quality health care services which don't cost the earth and are easy to find (I had to do an enormous amount of research to find the services my son needs) *Please monitor his medication... as it turns out I had to put in place that he could only get a week at a time for his medication so he never had a huge amount of tablets... sadly he can go to several doctors and several chemists to get more if he wants... Why is there no central register of drugs so his doctor can see the scripts and see if he has filled them and if he is picking them up regularly (often he forgets to get them, and I'm running around or worrying he will become psychotic again when he doesn't take them) *Thankfully through my work I have access to a psychology service which is Free, what would be great is if my son had this... once a month for a year, so he can really build a relationship and repour and deal with the root cause of his anxieties."

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

"*Please employ more men in the sector... I have found dealing with women all the time, can be challenging for a young man. And mental health is prominent in young men. More male role models and supports, recruit from ex army, navy, police and older men (over 55's) with life experiences... there are plenty out there as they are currently underemployed. *Call them mentors for mental health... and make it a Win Win... Over 55's men educating and supporting young men... *Retention... pay them well... and give them caseloads that are realistic "

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?

"My son who has a mental illness works. He runs his own business and is reasonably successful. Having a mental illness does not define you as unemployable...or that you can't run a business. What does need to be accommodated is to find a balance between work and health. Having flexibility is important and employers need to be aware of this. To improve social and economic participation, people living with mental illness can be involved with the community through the Neighbourhood House Network, they can complete courses or be involved in a range of classes. There are 375 Neighbourhood Houses in Victoria. There is also a range of opportunities in

employment through programs such as Jobactive. And a range of opportunities to run a micro-enterprise or small business through LaunchVic and Business Victoria and Good Shepherds LaunchMe Program. To realise these opportunities, people need to be educated... Not just let out of the hospital with no information or service opportunities, or leave the doctors or psychiatrist with just a prescription. We have a responsibility as a community to collaborate and offer a range of services based on peoples needs. Please create a website with all the collated services. So we know what is out there. "

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?

"*Funding for 500 new beds in private hospitals for inpatient addiction treatment (Detox) - approach the pharmaceutical companies to contribute as part of their Corporate Social Responsibility. *Build at least 4 Wellbeing facilities (800 beds) around Victoria which will support all aspects to Mental Health, these should include access to Psychiatrists, Psychologists, Exercise Physiologists, Dieticians, Willpower Programs, Addiction support, Detox, Meditation, outreach services and education for prevention *Funding for 100 new CATT teams across the state. Manned 24 hours a day. With a requirement, they visit with the person at least weekly. *A program which links older men (mentors) with young men to primary school to early teens to meet in schools once a month to mentor young men, particularly around mental illness - plenty of older men in Lions, Rotary, Sports Clubs (AFL), Golf clubs."

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

"Once the recommendations are completed, it will be hugely important for these to be implemented in a considered way. To ensure they last, please look long term.... as my son will need these services today and into the future. 10-20-30 years... When I may not be able to support him any longer. It may be a long time between Royal Commissions, so now is the opportunity to really fix the system. "

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

"I have been to hell and back in relation to mental illness with family members. More to the point, when I needed help (as a carer), I could not find it. I was heading towards mental health issues myself... however I realised that I could not afford to get sick, if I was to help my son, so through pure determination and willpower, worked through the system and found the solutions I needed. Not everyone has this opportunity. Facing the possible death of my child was gut-wrenching, I feel deeply for those that have lost loved ones due to a deficient system. And I have seen the gaps, they are gapping... it is time to fill the holes and really give anyone with mental illness the opportunity to get better. Thank you for taking the time to read my submission. "

IMPORTANT NOTE - PLEASE READ BEFORE USING THIS DOCUMENT

The author of this document has required that any information in this document which would allow another individual to be identified be redacted. Therefore, reasonable efforts must be made to remove all personal information (such as name, address, other contact details) and other information which could reasonably be expected to identify any other individual.

SUB.0002.0009.0034

A letter to my Son by



IMPORTANT NOTE - PLEASE READ BEFORE USING THIS DOCUMENT

The author of this document has required that any information in this document which would allow another individual to be identified be redacted. Therefore, reasonable efforts must be made to remove all personal information (such as name, address, other contact details) and other information which could reasonably be expected to identify any other individual.

SUB.0002.0009.0034_0002

I can't tell you how much I hurt. The pain just sits like a dull weight in my stomach. I ponder how to deal with it as I write this letter to you, hopefully by writing you the story it will help.

To my oldest, cleverest, risk taking, full of life [REDACTED]

You have always been an interesting child, testing your own limits and the limits of others. You tested me when you were born... I screamed from the pain of birth as your head was a bit large and forceps were used. You tested me in the following weeks when the temperature soared to 40 degrees and you had a fever and I could not cool you down. You tested me as a mother as I muddled through working out what your cries meant, there was no rule book and I often felt useless. You mainly tested me with your spontaneous character always wanting to experience everything, to do everything... I didn't know how to control you. Now I realise I should never have tried!

I know I wasn't a great mother, overprotective and continually giving you negative signals 'don't touch that' 'don't do that' 'don't go there'

Those simple commands were the foundation of your childhood and for this I am so very sorry.

We did though have good times, holidays, fishing, bike riding, I encouraged you with little charts and rewards.

You were though your Nonno and Nonnas pure joy. You were the absolute light of their life and you could do no wrong. They loved you unconditionally.

I also loved you, but in a different way. I could not understand you. You were chaos, I was control.

In your teenage years your path led to smoking, drinking, using drugs, cutting yourself, self harm. We tried to help, and in hindsight should have sought counselling then. Those days were hard and through it all we were there for you.

The worst days though were when your relationship with girls went sour. You did not cope well.

When you met [REDACTED] in your early twenties, we thought you had found the right one. As it turned out this was not meant to be. When things didn't work out, you got a gun and nearly ran the car into your brother. Again we returned home to help you.

Then you went to Perth and met [REDACTED]

You settled into a life together. You travelled and we thought the chaos had finally settled. But this was also not meant to be.

You both returned to [REDACTED] but needed your space. You separated. Then you decided to take off up north. [REDACTED] wanted to go with you. You both ended up in Perth. Then you returned to Melbourne without [REDACTED]

We cannot know what you were going through, only that you did not seem to be able find peace in yourself. You chased happiness, yet happiness is not the feeling of always being elated. Happiness is a total feeling of comfort, peace and being grateful for who you are and what you have. Happiness is living in the moment and appreciating it for what it is.

IMPORTANT NOTE - PLEASE READ BEFORE USING THIS DOCUMENT

The author of this document has required that any information in this document which would allow another individual to be identified be redacted. Therefore, reasonable efforts must be made to remove all personal information (such as name, address, other contact details) and other information which could reasonably be expected to identify any other individual.

SUB.0002.0009.0034_0003

Your on off again relationship with [REDACTED] was a problem. One day you asked me what you should do. I said you needed to decide one way or the other. If you loved her, go to her. If you didn't love her stay home. The decision had to be yours. That was in March 2017.

You decided not to go, but we knew you were talking to her on the phone. We couldn't help, you wouldn't let us in.

At the time we did not know you were taking illicit drugs - cocaine and others and we didn't know for how long.

Early April you told us you were going to a doctor who was referring you to a Psychiatrist.

On the 10th of April you collected 2 boxes of 100 tablets x 500gm of Sodium Valporate and Fluextine. A mood depressant and an anti depressant. These should have lasted you until mid July if you were taking 2 tablets (1000 mg a day).

When you told me, I had this feeling of dread. In the past prescription drugs seemed to always take you down the wrong path.

You went to see [REDACTED] for Easter and stayed with her. You must have been drinking and combining this with the drugs as you tried to jump a fence on the 23rd of April and ended up with a broken rib.

You returned to work in Melbourne. Then things went sour between you both. You broke up.

Over the past few weeks you said you seemed happy enough.

Yet you don't realise what we were seeing... A young man who's heart is broken and who is trying to mask his hurt with prescription drugs and alcohol, wild nights out and sex with other women. This is not happiness, it is escape!

Then on the 30th of May the doctor changed the dosages and gave you another box of 200mg x 200 tablets.

Your Chaos spiralled out of control...

Wednesday around [REDACTED] you texted your Dad about the change in the Medication. You said you may be a bit funny. We realised you needed us again and suggested you stay with us from the next night.

[REDACTED] I flew out of bed when I heard the car and I instantly knew something was wrong. I went out to see you on the driveway, you staggered out of your car and mumbled something about your car being in an accident and the police. You came in and I could see your eyes were all over the place.

I called out to your Dad to get up and went and rang an ambulance. We knew you had taken the drugs but what and how many we could not tell.

You were extremely agitated and mentioned to your Dad that you would be in a Coma in 4 hours and dead in 6 hours.

000 asked me what you had taken, I was calm but absolute desperate inside - you said 200 Sodium Valporate.

IMPORTANT NOTE - PLEASE READ BEFORE USING THIS DOCUMENT

The author of this document has required that any information in this document which would allow another individual to be identified be redacted. Therefore, reasonable efforts must be made to remove all personal information (such as name, address, other contact details) and other information which could reasonably be expected to identify any other individual.

SUB.0002.0009.0034_0004

Within 10 minutes you were unconscious. Dad put you on your side and we waited for the ambulance. They came 10 minutes later and it took another 20 minutes or so to get you into the Ambulance.

They made the decision to go to [REDACTED] which had an ICU. Both [REDACTED] and [REDACTED] don't have one. This was a critical decision, as they would be able to deal with this sort of emergency.

We followed the ambulance but had to wait in the waiting room for 15 minutes. My mind was racing, questioning what had triggered you do such a thing? I asked myself this question many times over the next few days.

When we finally got in to see you, they had treated you for a heroin overdose. We explained that it was prescription "sodium" something. Dave the nurse knew straight away "Sodium Valproate." Yes - 200 tablets.

They put a breathing tube down your throat as your breath was now laboured. They put another tube into your stomach and started treating you with charcoal. They put you into an induced coma and sent off bloods.

Richard the ER Doctor was onto it. It was 2.50 am in the morning. He realised at one point if they gave you too much fluid you could have a cerebral oedema - swelling of the brain. So they stopped this.

By 5 am your bloods were back. Levels at 12,000. Way above the 7000 that is considered life threatening.

We had to contact [REDACTED] and tell him. He had to go to the house to find out what else you had taken. He only found empty boxes and empty bubble packs. 2 x 500mg Total 200 tablets and 1 x 200mg Total 200 tablets. 400 tablets in total. You told us you took 200 tablets, we still can't account for another 100 tablets!!

At 7 am they transferred you to the ICU. There was a toxicology doctor Ben there and another registrar Mim (I think) and Isaac the nurse who would look after you.

They would be your life savers!

A dialysis machine was brought in to filter your blood and flush out the drugs. At 10 am your levels peaked at 15,000.

You were close to Death.

The doctors and nurses kept going though.

I was frantic inside. The adrenaline had kicked in, this was keeping me alert and awake. But I could not stop the anguish I was feeling. Were you still in there.

We dashed home to get changed and pick up the Van. I had to call [REDACTED] to tell him. He was distraught and wanted to come home [REDACTED]. I cried, what could I say except that we would keep in touch.

Around mid afternoon Issac mentioned that you had, had a release of fluid into the Catheter. He mentioned that it was an ominous sign of swelling of the brain. Cerebral Odema.

IMPORTANT NOTE - PLEASE READ BEFORE USING THIS DOCUMENT

The author of this document has required that any information in this document which would allow another individual to be identified be redacted. Therefore, reasonable efforts must be made to remove all personal information (such as name, address, other contact details) and other information which could reasonably be expected to identify any other individual.

SUB.0002.0009.0034_0005

Your dad and I went for a walk. Your dad mentioned to me that he thought "we might lose you" and "to be prepared".

I have never seen him cry, except when his Mum died and when we were in [REDACTED] and he wanted to get home.

But he looked at me, tears welling in his eyes and I could see the absolute pain behind his words. He wanted you to be ok but didn't know how to make it so.

I said between the tears "Nonna could not have you yet" We stood outside the hospital and hugged each other, hoping desperately that you would be ok.

The hospital staff kept going, problem solving the issues.

The dialysis machine was running at 250 litres of blood per hour instead of the normal 100 - 200 per hour. Running it fast meant it clogged up with cloats and needed to be changed. Each time you lost 1/2 litre of blood. We stayed in the Van outside the hospital so we could be close.

They kept giving you charcoal to neutralise the drug. We held your hand talking to you and again wondering what had triggered you to do such a thing?

Your vital signs weren't good. Sodium levels were increasing and the filter kept crashing. The doctor suggested lactulose to get you to poo out as much of this horrible stuff as possible.

Over the hours the levels slowly decreased by Friday evening the levels were at 10,000.

Marilyn your night nurse on Friday night, very gently washed your mouth, cleaned up your sick and cleaned up your bowel movements. The levels by Saturday morning were at 3000. The filter was doing its job but had crashed 4 times and each time you lost 1/2 litre of blood.

I went in to see you around 5.30 am. You were moving slightly, a promising sign. To settle you I sang you Toorah Loorah. My heart was breaking but I had hope.

Saturday was the really hard day. They had been sedating you but now needed to try and wake you up to see what your brain function was. Around 11 am the doctor had the sedative taken off. Your arms had been put in straps so you did not pull the lines out. You were still on the filter and they could not risk you knocking the tube in your groin.

You were in there but it was hard to tell if it was all of you.

You sometimes obeyed commands "open your eyes" "squeeze my hand" you were not consistent so it was hard to tell if you were ok.

Jane the day nurse was amazing and a great support to you and us. It is hard to believe she only earns a lousy \$33 per hour.

Your dad contacted [REDACTED] and I heard him say " We think we will be taking him home, but were are not sure in what state".

Then over a few hours Saturday Afternoon, you came back to us.

We held your hand, asked you questions and you responded.

They decided to take the tube out of your throat.

IMPORTANT NOTE - PLEASE READ BEFORE USING THIS DOCUMENT

The author of this document has required that any information in this document which would allow another individual to be identified be redacted. Therefore, reasonable efforts must be made to remove all personal information (such as name, address, other contact details) and other information which could reasonably be expected to identify any other individual.

SUB.0002.0009.0034_0006

The breathing tube that had protected your lungs and the stomach tube to put charcoal down and suction your stomach. Both had helped save your life.

Your first words "thank F**K for that"

Now that we knew you were with us, we could start figuring out what had happened.

Both of us had thought that you had been in touch with [REDACTED] on the Wednesday night and that this had triggered it.

But I now know that it is much more than this. No one consciously takes a massive overdose (the highest seen) of a drug they know will kill them unless they need serious help.

And you have access to Serious Help Now!

You must want to survive or you would not have driven to our house. Each critical decision (and there were many) has brought you back so you can LIVE!

I know you have a problem, it could be Bi Polar it may not be, that is for the professionals and counsellors to figure out.

You certainly struggle to deal with emotional lows, particularly those that really hurt, those that don't make life worth living. But many of us have had to do the same and deal with really heart breaking life choices, but we get through by talking to others, my letting the emotions in and dealing with them, not running from them.

Dad pointed out that you turn to self help when you feel down. Illicit drugs - cocaine and others and when these get too expensive or are hard to get - prescription drugs.

Blaming the drugs for what has happened is the same as blaming someone else for putting them down your throat. Only you can get counselling, only you can tell the whole truth to the doctors and to us. Only you can suffer through the lows without relying on drugs to get you through.

Dad and I have also realised that there is very little we can do, other than be there as a listening ear.

You now have a choice.

You are so clever, smart, fun to be around... you have so much to give to others.

You can use this opportunity as a 2nd chance and go in the right direction. Or continue with drugs and try and muddle through.

I know I never want to be here again. Facing the death of a child is the most heartbreaking low I will ever experience. Please don't make me go here again.

[REDACTED] it is up to you!

Love you

Mum