

25<sup>th</sup> June 2019

Royal Commission into Victoria's Mental Health System  
PO Box 12079  
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*rcvmhs.vic.gov.au/submissions*

We appreciate this opportunity to express our thoughts and feelings to The Royal Commission into Victoria's Mental Health System.

Our input is shaped by our experiences over the past 25 years caring for an adult son who has been living with mental illness and an ABI over this period, and unfortunately has had in excess of 6 traumatic admissions.

We are now aged in our 70's and finding it increasingly difficult to manage his episodes when untreated, as he becomes violent, irrational and a threat to us, extended family members and to society.

Management and advocacy becomes more taxing as we age and without constant effort things seem to have a natural tendency to go awry.

Our son is compliant Under a Treatment Order responding extremely well and able to become a well-respected member of our family and of society and to live independently work on a part-time basis when available and generally to enjoy life.

The Mental Health Review Board process at the end of the CTO is difficult, as to all intents and purposes our son has been seen as recovered following the Treatment Order and unless we campaign vigorously to advise of his previous non compliance he is discharged from the CTO (usually to the care of a GP) only to soon relapse and the "revolving door" process starts again.

Dealing with this situation has been difficult and stressful and has required enormous strength, determination and intelligence, far more in fact than we possess and so we simply keep on doing the best we can.

Over the years many shortcomings in the system have come to light:

In some sort of order we have outlined some of the major issues, which we have come across.

### **Getting help – Paths to Intervention**

At times of crisis the only effective portal to treatment is through triage and the CAT Team in liaison with police, which is not a well-known procedure to ordinary people and is difficult to access and navigate and fraught with difficulty and danger to all concerned .

### **The first question is where do you even start?**

With all respect to these great organizations and with the best will in the world Lifeline or Beyond Blue, etc .are not necessarily of great help at this stage.

### **Once hospitalised**

Hospital stays are usually extremely short and ineffective without adequate communication with Carers or family – requiring much perseverance by Carers to obtain any effective treatment plan or rehabilitation. Most of us have little capacity to push against the systemic and seemingly uncaring beurocracy of the hospital system

We were often shocked to find our son released from hospital without our knowledge or communication to us and with little care for the welfare of our son or ourselves

We feel that the duty of care from the hospitals upon discharge is lacking or extremely ineffective.

### **Upon discharge from hospital**

In our case the cyclic nature of my son’s engagement with the Mental Health System and the treatment of his chronic condition coupled with his complete lack of insight means that treatment is usually given only after a lengthy episode of extreme difficulty and distress as a CTO. He responds well to the CTO and when reviewed by the Mental Health Review Board he has been in the past been accepted as “well” and discharged to a GP to self manage unfortunately this takes no account of his actual lack of ability to do so. (In part due to his complete lack of insight).

Unfortunately liaison between the GP and the Mental Health System quickly fails leading to a re-establishment of the cycle of several years of sickness and eventual intervention by authorities with all the risk and problems involved. This cycle in his health is very obvious to us and to family and friends. We have no ability to obtain help other than to contact Triage and Police when situations become acute and difficult and to start at the beginning again with no support for all involved.

We see a strong need for the availability of an ongoing long term CTO where beneficial in order to ameliorate the stress of annual Mental Health Boards of Review and the distress of the current “hit and miss” system of treatment where treatment is likely to extend for the duration of the order then collapse.

**Carers consumers and family**

Consumers, Carers and family are struggling to deal with an enormously difficult situation with virtually no tools, training, capability or authority to instigate, manage or be involved with any treatment.

Bear in mind that these are the people who put in more time, care, love, despair, hope and any other emotion you can think of more than any professional can begin to imagine.

**Management and timeliness**

Obtaining effective, prompt and on-going management has been a major factor in treating our son's illness it seems to take some years from the onset of an episode for diagnosis and treatment to occur. Treatment is mainly short-term and in the case of chronic conditions, inadequate or early withdrawal of treatment leads to further relapse and increased resistance to treatment. Currently a common cycle would be two to three years of illness followed by a short hospital stay of a week or less then three to twelve months of ongoing treatment provided, if a CTO is in place. Once the CTO expires or is reviewed the consumer is released to self manage ie: under GP care, which in many cases does not continue and relapse follows

**Overall health**

In our opinion it appears that while the Mental Health System works with the mental health issues of a consumer very little attention is paid to their general overall health ie: dental, flu injections, general checkups, etc. Which is an important factor in general and is also a great help to maintaining mental health .

Very few people who have not been involved with being drawn into this system would have any idea what an awful traumatizing terrifying and demeaning experience it is.

Unbelievably access to care does not become in any way easier on subsequent occasions.

Continuity and consistency of overseen treatment (over the last three years) has been enormously helpful and successful in allowing our son to return to being a well-regarded person in the community and amongst his family. We do believe that further ongoing improvement is very possible and probable and we are looking forward to seeing our son yet be the best that he can be with continued care.

**Accommodation**

Cyclic illness, lack of funds, lack of stability and often lack of family support makes it difficult or impossible to maintain continuity of housing or any housing at all. There is very little affordable accommodation available let alone anything that is at all adequate.

**Employment**

Many or most consumers would aspire to employment at some level but without continuous help and management and wellness there is little opportunity.

**Benefit of Effective treatment.**

Firstly to the consumer who may have an enormously improved and fulfilled life in our society would surely be considered to have some expectation or right to available treatment.

Benefit to the family and friends of the consumer who are often strongly involved and affected by the illness of their loved one.

Benefits to society, which has already taken a large financial return in the closing of hospitals and institutions, which had previously dealt with these issues albeit in an old fashioned and less humane manner.

The potential return to society in employment and productivity and good citizenship would be of an enormous benefit to all.

The prevention of the crimes and social disasters, which can follow poor or no management.

**Housing**

Due to the lack of adequate subsidised housing we have chosen to provide over the past 25 years to provide accommodation causing financial constraints to us with no recognition or allowance for pension issues now that we are at retirement age, causing issues with siblings and long term finances.

In conclusion we think that there is benefit to effective and ongoing treatment to the consumer, family and society instead of the on-going roller coaster as we have experienced.

Our family member is a valued member of our family and deserves and needs the effect treatment to enable him to maintain himself as a worthwhile member of the community.

We thank you again for this opportunity

Yours sincerely



### **A brief synopsis of our thoughts**

One of the most frustrating and important things for us is that the tools and resources are available to enable a good outcome in most cases, as has so nearly happened for us several times over the last 25 years or so, all that seems to be missing is the will and application to utilize them.

Access to help or treatment is difficult and obscure for either the person suffering or for their family or Carers and can involve a dangerous and highly exposed position in many cases.

Respect all round should be given and expected, workers have a right to expect that respect and those struggling to navigate a complex and stressful system should deserve similar respect. Respect for the consumer is sometimes difficult the true nature of the person being often hidden under layers of mental illness particularly during a difficult time, but is none the less vital to help establish trust and a faith that the system is capable of being beneficial.

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Liaison between GP's and Mental Health System usually fails quickly leading to re-establishment of the cycle of sickness and re-intervention.

The system does often subscribe to the belief that should they not have seen the consumer for some time then that has been a time of wellness. In our experience the opposite is true, this is a time of being "off the radar" and suffering alone and with little or no support.

It is our belief that the model of treatment (post hospitalisation) that we personally have witnessed over the last three years has moved a long way towards addressing some of these issues and has gone a long way towards fulfilling our hopes for the future and for our son's well being. We believe it would be of great benefit were this model able to continue for us and to be more widely available for others.