Re: Royal Commission into Mental Health

7/6/19

To Whom It May Concern,

There is indisputable evidence that what keeps people, suffering from a mental illness, well and out of hospital, is a team effort by family, friends and clinical staff.

We have been living with 17 years of mental illness in our family, a history of early warning signs followed by hospitalisation and recovery. Communication and information sharing between carers and the consumer's treating team is invaluable to aid timely intervention to help prevent and alleviate many of the consequences of a mental illness episode.

Our 35 year old son has a 17 year history of mental illness. When he becomes unwell we see the all too familiar collapse of his insight, leading to distrust, paranoia, inappropriateness and threats. This is not our son, it is a mental illness who moves in and takes him from us. When our son is well he is the most charming, loving, kind, compassionate, interesting person with hobbies, hopes and dreams just like all of us. Mental illness robs him of all of this when he is unwell.

18 months ago he once again made the decision to try and come off his medication, with the assistance of his treating team. He dreams of not being labelled with mental illness and hopes to be free of drugs with unpleasant side effects. We were scared but 'maybe this time he will be OK'. Sadly for him it was not to be and once again we had to stand by and watch him unravel (he trying desperately to keep a lid on things until sadly he lost all insight) and was eventually humiliated by landing back in hospital (approx. 10 admissions to date) A month in hospital (which seems to be the norm) and then many months for him to get back on his feet. Once again we were devastated and felt helpless and hopeless, that despite all the warning signs he was allowed to spiral out of control, despite the efforts of his treating team and us, his carers, who had to sit on the sidelines holding their breathe. There was little we could do, not to mention the despair, anxiety and impact on our son, and the rest of his family.

We understand the importance of early intervention and are all too familiar with the early warning signs but despite this, we are told on the flip side, that we will just have to 'sit tight' and wait. Intervention can't occur until something BAD happens. What? Wait till he gets hurt? Wait till he hurts someone else? Wait till he is incarcerated for something that is completely out of character and avoidable? Wait till it all becomes too much for him and he decides that his life is just too hard and not worth living? We are bewildered and scared.

For the family (carers) and treating team to have their 'hands tied' seems ludicrous and deeply troubling. Carers need a voice to be able to help, assist and protect their loved ones, to be able to share information and their concerns which will be taken seriously and validated.

As far as possible, whilst still respecting the individual consumer, information sharing, is vital, especially when the consumer starts to unravel and become unwell. From our experience, it is too late and impossible to ask for cooperation from the consumer during an episode. An Advanced Statement needs to be agreed upon when the consumer is well and implemented in a timely manner to provide a safety net to keep our love one and everybody safe and well.

Further to this, could a Community Treatment Order, which has been placed on our son in the past and provided structured support, be reinstated when all the signs point to someone losing insight and at risk? Rather than wait till the inevitable and they become so unwell that hospital is the only option.

Here are our key points:-

- 1. We saw deterioration before the clinicians.
- 2. The Mental Health Act didn't allow early intervention.
- 3. Information sharing between Carers and Clinicians with Consumers (Individual's) freedom and privacy respected and considered

Communication and information sharing is invaluable to aid timely intervention to help alleviate and/or prevent many of the consequences of a mental illness episode. It is a humane response to any complex, debilitating illness, whether it be mental or physical.

Thank you for the opportunity to share our experience and opinions.

Yours sincerely,

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

SUB. 0002.0028.0044

Name

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

"Positive media stories about people living and coping with Mental Illness. We often hear when a crime is committed my someone suffering from a mental illness. This reinforces and promotes fear and misunderstanding about the majority of people who are law abiding citizens, managing and living with a mental illness. Employment: Encouraging meaningful work and activities. Education and support in schools about Mental Illness and encouraging open dialogue and discussion about Mental Illness. On going training in emergency services and police to receive the latest training to assist when dealing with people with mental health issues. "

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?

More funding for training in Mental Health and to increase Mental Health workforce and support staff.

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

"Early intervention, information sharing and communication which is validated and acted upon in a timely manner. "

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.

Loneliness is a huge problem. Feeling different and embarrassed about label of mental illness. Lack of insight and acceptance of their mental health.

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

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

Carers need to be heard and their concerns taken seriously and validated. Carers need the support of case management also.

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

Better wages and conditions. More training and education.

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?

Loneliness and employment is a big issue for consumers. Providing more opportunities for them to be gainfully employed.

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? Communication and information sharing between carers and the consumer's treating team.

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

Is there anything else you would like to share with the Royal Commission? $\ensuremath{\mathsf{N/A}}$