

My Story

I do not wish to have my name (or my son's name) recorded as part of the Royal Commission process.

I have been a carer for my beautiful, highly sensitive, intelligent twenty-six year old son for the past eleven years.

Over these years my son has had admissions to both the adolescent and the adult inpatient mental health services of two large Melbourne public hospitals.

On the first occasion, at age sixteen, he was an involuntary inpatient for three months....and on his most recent admission he experienced a most serious and traumatic sexual assault by another male inpatient at night.

I now wonder constantly whether my son can keep going, risking further encounters with a mental health system which took away his right to make decisions for himself and, worse still, failed to uphold his basic human right to be safe at a time when he was most unwell and in need of care Or whether, instead, he will choose to no longer endure the inner turmoil of his mental illness and to never be at risk again of experiencing immeasurable trauma in a mental health facility. He has already attempted to seriously harm himself on several occasions before, which further heightens his risk of suicide in the future.

My son's serious mental illness has meant that, despite his intellectual capacity and warm personality, he has been unable to secure work or had the ability to sustain study and maintain trusting friendships.

We have built a small bedsit attached to our home in order to keep our son close to our family's loving care, and at the same time to provide him with safe and secure housing which he would otherwise be unable to afford.

Our son and our entire family have been on a long and at times incredibly distressing journey over eleven long years.

As a carer I have found this journey to be profoundly life changing, with the impact largely underestimated by the mental health practitioners we have been in contact with. It has left me feeling in a constant state of anxiety.

The word "journey" is often overused today....but in the case of mental illness I consider it appropriate, as it captures the experience of people living with a mental illness and that of families travelling with them.

The journey for me and my husband and other children has been bewildering and many times literally terrifying. There have been endless bumps and derailments along the way, and, with little in the way of guidebooks, we simply have had no idea what to expect each day as we have travelled along, let alone developed any confidence about our final destination.

Despite a countless stream of encounters with others there have been few close companions to truly share our struggles with. Instead it has so often been a lonely and isolating journey, filled with fear and uncertainty.

But you just have to keep going on this road, you fall, you pick yourself up again ... and again ... and struggle on.....because there is a precious young person who needs you to stay beside him....

Grief

I consider that grief is central to the experience of mental illness, both for the person living with challenging mental health issues and for the carers and family members deeply affected as well.

For carers, grief is often invisible and not named. It is not publicly acknowledged, and it is poorly understood. It is ever present but often dismissed.

It has to be put into abeyance while there are crises to be dealt with. It has no beginning, no end. As a carer you have no framework for these feelings, and there is no resolution to your grief.

It is complicated by the fact that the lost person being grieved for is present and in pain and you simply cannot do anything to ease their pain.

Around mental health professionals, your grief must be hidden, otherwise you risk being labelled and your grief used instead to discount your standing as a carer.

Grief never goes away, rather, over time, it just continues to deepen....

The painful loss in mental illness

For carers and families of people with mental illness the painful experience of loss is profound and ongoing, as one continually observes a loved one struggling to live with their illness.

Your loved one loses the simple enjoyment of life, the ability to reach their full potential or to experience any sense of fulfilment of a meaningful life, and also loses a sense of control over their own life.

For carers there is deep sadness in the loss of the life your family had before the disruption caused by mental illness.

You lose the easy, ordinary lightness of life. You feel helpless, and despair at having no power to alleviate the suffering of the one you love. Instead you feel anguish at seeing no place for your loved one in the world.

And you lose your family's privacy by an intrusive mental health system.

Caring has impacted upon my mental health too.

As a carer, I have felt chronic sorrow. It has entered my life and led to accumulated layers of negative thoughts and often unhelpful patterns of behaviour including feeling helpless, bitter, frustrated, angry and isolated.

My caring role has led me to be forever hyper vigilant and to feel fear and anxiety and despair like I have never known before.....

How to best support the needs of family members and carers of people living with mental illness:

- Identify and consult with carers / family members at all stages of a person's mental health journey.
- Identify the challenges that issues of privacy / consent / confidentiality pose in terms of carers'/ families' communication with mental health clinicians, especially at critical points of care, e.g. discharge planning.
- Focus care on "relational recovery", not just on individual-centred recovery.
- Better recognise, respect, engage and support parents/carers as therapeutic partners in providing support to people with mental health challenges.
- Provide more face-to-face access to ongoing counselling services for families and carers of people with mental illness.
- Require all mental health services to demonstrate family-inclusive practice as per the "Working Together With Families and Carers - Chief Psychiatrist's Guidelines".
- Provide clear resolution pathways within mental health services and also a complaints mechanism to the Mental Health Complaints Commission which allows carers to reflect on standards of care of mental health services **without a consumer's consent**.

What would improve the system?

- Establish ways to identify early at-risk groups of children and young people, predisposing factors, and underlying causes of mental illness, including the impact of early trauma on the emotional health and wellbeing of children and young people.
- Provide free, early, effective therapeutic parenting programs to parents and caregivers of children and teenagers.
- Fund specialised therapeutic services for disturbed children and young people early in order to avoid crisis-driven approach to services later.
- Expand the range of specialist educational programs available to children who struggle to fit in to mainstream education, and ensure teaching staff in these settings are trained in trauma-informed practice.
- Provide early training, and then ongoing education, in evidence-based trauma-informed practice, for as many professionals as possible who engage with children and young people in the community (e.g. education staff / health professionals / police / child care / child welfare agencies).
- Educate GPs better in early detection and management of mental health challenges, especially in children and young people.
- Bring back locally-based community health operated mental health services and early, responsive one-on-one support to young people affected by mental illness and their carers / families to help avoid admission to hospitals or to area mental health services.

What would improve the mental health outcomes and improve access to, and the navigation of, Victoria's mental health system for people of all ages?

- Ensure the implementation of best practice mental health treatment and care models that are person-centred and family-inclusive.
 - Require staff working in all mental health fields to have a minimum level of mental health training and then require ongoing education and training in best practice mental health care.
 - Identify the therapeutic importance of the impact of staff retention and of continuity of care in mental health services. Highlight that personal connection and understanding are intrinsic to the therapeutic trusting relationship between child/young person and clinician and their carers.
 - Build a greater peer support workforce / greater consumer and carer lived experienced staff.
 - Ensure that consultation with parents / carers / families is considered essential to best practice in all mental health services and create KPIs to monitor this.
 - Strengthen options for community-based treatment and supports to prevent and reduce admissions to acute mental health inpatient units.
 - Identify the need for breaches of sexual safety in mental health facilities to be recognised as serious violations of an individual's human rights which cause immeasurable trauma, and for such incidents to receive priority attention by mental health services.
 - Develop a comprehensive Victorian Sexual Safety Strategy for preventing and responding to breaches of sexual safety in mental health inpatient units.
 - Implement all of the recommendations of the MHCC sexual safety project report - "The Right To Be Safe Report" - i.e. by addressing the need for strong leadership and governance, for changes in culture and practice, for improvements in designs of mental health inpatient and emergency department environments e.g. single rooms, not just gender separate areas.
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- Highlight the need for Victoria's Mandatory Sentencing laws for people who injure first responders to be retracted, and instead return to the courts being left consider all the circumstances which lead to someone responding in this way. Identify that people who for example have had very disturbing experiences in Victoria's acute mental health inpatient units may be determined to resist any attempt to have them intercepted by police and readmitted to a mental health facility.