

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 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.