

A Carers Story

Good morning every one and welcome to this very special annual event. I commend the organisers for such an initiative. I stand tall and proud and I feel very honoured to be given the opportunity to speak to you.

Mental illness is not a crime.

Let me start with a brief outline of my story, a story which has led my family to this point.

When my husband and I attempted to start a much longed for family, it didn't happen. But after a very testing time and some excellent medical intervention, we were rewarded with two amazing children; a special daughter followed two years later by an amazing son. I would never say their childhood was normal or ordinary, as every day we have felt most fortunate to have them. We have valued their presence and all our lives they have continued to delight, and, at times, challenge us.

As our son approached his late teen years, what for so many of our young people is seen as a youthful experiment, for him became a 12 year trip into a nightmarish limbo. Almost as soon as he started to flirt with substances he began to suffer from the symptoms of schizophrenia. We lost our bright, outgoing, outdoors, full of life son as an illness we knew little of swallowed much of his personality and tried to take him from us. The greatest challenge for his family and his clinicians alike was that he embraced his illness...it made him feel special and gave him grandiose feelings. He felt he had been sent to save the world and unfortunately the more substances he abused, the more special he felt his powers were.

In the 12 years following, he had no insight at all into his illness and we could do little as a family but stand beside him as he navigated his way through, and in and out and "round about", the mental health system and even, to our horror, the criminal justice system. I will admit the whole experience rocked us to the core.

We were often shocked at the injustice of it all, frequently feeling totally powerless and alienated.

We do not blame any single person, but let me give you an insight into how this happened. Our son only really responds to one medication. At one point his treating team decided, against family wishes, to change his medication. They did not hospitalise him to do this. He became very unwell very quickly and in spite of the family requesting urgent hospitalisation over a period of weeks, he remained in the community and continued deteriorating to such a point that, because of his illness, he was seeing every moving person as a threat to him. One day he attacked some strangers. Thankfully he did not harm anyone in this random attack but he was arrested shortly afterwards and thrown into jail.

Now pause a minute and reflect on this. A young man becomes unwell, is seen a number of times by his treating team and is not hospitalised, becomes more unwell as a result and is thrown into jail when he is at his most vulnerable. Initially he is left un-medicated to become even more unwell. He finds himself in handcuffs, guarded by burly armed guards, led into a courtroom and isolated in the locked section of the dock, unable to even speak to his family who sit terrified and silent in the gallery, unable to believe what is happening. He is then returned to a large windowless transportation vehicle and driven over 180kms from his home town and thrown into a State Remand Centre. Here the family is allowed restricted visits and yes, they feel shame and guilt and self blame for their inability to protect someone so precious from this mal treatment.

Mental illness is not a crime. We cannot continue to allow it to be treated as one. How dare we as a society persist in thinking that it is okay to let our mentally ill deteriorate to such a point that we can justify throwing them into jail? On the "Insight" program: Minds at Risk, Ian Pike, the chairman of the NSW parole authority and a former Chief magistrate tells us: 41% of ALL inmates have had some prior treatment for a mental health problem. 15% who enter custody are currently on medication for a mental health illness. On a 2001 screening survey, 27.5% of prisoners met the criteria for referral for Schizophrenia, a further 19.5%

for bipolar disorder and 48.1% for depression. When asked by Jenny Brockie “.....when people say Jails have become the new hospitals for Mental illness is that a reasonable description?” Ian Pike replies “I think it is...”

I alone know personally of three families, ordinary families like you and me, this year whose mentally ill sons have been sent to jail as a direct result of actions taken because of their mental deterioration. In all cases, the family has been pleading for intervention from the mental Health Systems, but as we know, our Mental Health systems are overloaded and underfunded. This sick system is trying to do its best but I believe simply does not have the resources.

And that is partly why I am speaking to you today. Recently I had the pleasure of listening to our Australian of the year, Patrick McGorry, speak. He spoke about stigma and one of the points he made which for me really hit home was that as long as we continue to hide mental illness and not discuss it, successive governments will continue to ignore it. We can no longer allow that to happen. And it goes without saying that when people discuss issues openly it usually leads to greater awareness and understanding.

Helen Keller once said, “Alone we can do so little. Together we can do so much.” That’s why this walk and annual event is so very important. And I believe it is vital that we unite with the many dedicated workers who I imagine must feel frustrated at times by the lack of funding and resources.

Today I want to offer families and carers some hope. Our son did finally receive some excellent care in the Mental Health system. Some years after his release from jail he was placed in the Lake Macquarie Psychiatric Rehabilitation program at Moriset and over an extended period of time on the correct treatment with ongoing intervention and support, to our family’s amazement and disbelief, he is currently the most well he has been for over 12 years. We are extremely grateful to the skilled professionals who work there and we consider that our son was very lucky to have them come into his life. These, I believe, are the types of institutions that we need more of, and again we need to agitate for greater funding in this area.

At points on our journey, we had felt completely hopeless. We reached the point where we dare not hope. Throughout our darkest days some wonderful people at group support meetings would say, "Don't give up hope," but we stopped believing and if you'd asked us a year and a half ago if we thought our son would ever be this well again, we'd have laughed It seemed like an impossible dream....so hang in there. Given correct treatment, and a strong person, miracles do happen.

I know things can change any time but our son is now living independently with a Neami package and ongoing support from some wonderful people at supported recovery. We are very lucky and he is doing so well.The systems put in place for him are wonderful. I wish that there were more of these support systems for all in need..... and I sometimes find myself feeling guilty that others in need are not yet receiving this level of care.

I never thought I would reach this place, and in the middle of our murkiest times it was sometimes hard to put things in perspective, but I want to alert you all to the greatest hero of our story...our son.

He is a survivor. He continues to deal with a massive mental illness which has, in his prime, changed the course of his life. He sees his friends and peers contributing to society. He sees his friends and peers buying houses, starting families. He sees his beautiful cousins heading off to university. He initially fought against, and then accepted a disability pension and continues to battle to live within his means. He has been keenly aware of the stigma surrounding mental illness. It takes real courage to survive the treatment of being thrown into jail for something you have no control of, but even greater courage to return to your community afterwards, knowing that all local media have named you in sensationalised reports which showed a total lack of insight into the dignity of those who suffer from mental illness.

I am so very proud of him. Throughout the past 12 years, he has maintained a wonderful witty sense of humour ...even when on the acute ward he continued to delight us with this side of his personality. On a short half-hour leave, he went straight to a surf shop to buy a new t-shirt and came back to the ward with a shirt

emblazoned, "Free Will". His name is Will....and he wore that shirt on the ward every day. He plays the guitar beautifully and we have been privileged to listen to the beautiful music he creates.

And to all families and carers who have someone who suffers from mental illness, remember these things:

- no-one is to blame, not you, not the person who is ill.
- it takes real courage to live with any illness but a special sort of courage, I believe, to deal with mental illness, especially in the face of the stigma, fear, lack of understanding and alienation.
- Having mental illness in a family helps us all to grow in ways we could never have predicted. It takes time to accept but start today....give yourself a pat on the back...you too have grown. Being here today is evidence of that.

The other day, I drove out of my suburb and noticed a row of freshly planted tall, advanced, young saplings. I felt pleased and proud of a community which was obviously trying to beautify the surroundings. A few days later I noticed a whole row of the new plants had been pushed over. They were at a 45 degree angle and I was saddenedbut not for long because within a day, I noticed someone had been and straightened them all and you could hardly see the difference between these few trees and those further up the street. I felt another rush of pride. They had survived. A couple of more weeks passed and again I was stricken to see a repeated action. The same trees which had just begun to strive out were tilted at an awkward 45 degree angle. I hope they'd be helped once more and sure enough, within a few short days, they were standing proud. I wondered how long this would last this time. A few quiet weeks past and just recently I drove by and as usual, glanced at my favourites, the gutsy trees. To my dismay, I discovered that a single branch on each of my heroic trees had been bent downward, and hung forlornly and limply, broken in the breeze. The trees further up the street had not been touched, and continued to grow tall and strong, oblivious to the plight and battles of their nearby cohorts. Maybe a couple of nearby trees had glanced hastily over their shoulders and having slept blissfully through the late night attacks, tut-tutted and murmured, "Oh dear. What happened there?"

before turning away quickly for fear of involvement and contamination. As in the past, someone came and tended to the injured limbs, sheering them off and painting them with a protective substance to keep out disease. And I realised that “my” trees had become closer to my heart. They would forever be different from the other trees....but you know what? The differences won't all be bad. We know what happens to trees that are pruned, cut back. I am waiting with hope to see after a few years growth the beauty of “my” trees. I am sure they will be special, they will certainly be more resilient and am confident in many ways they will be even more vibrant and beautiful than those untouched further up the street. And I will share a pride in their beauty.

My hope today is that society too, with our help, will come to recognise and value those who have gone through adversity and share our pride. More than this, my hope is that, as a result, society will begin to truly meet the needs of those who suffer from a mental illness.

Finally let me leave you with this thought from H. Jackson Brown, "In the confrontation between the stream and the rock, the stream always wins- not through strength but by perseverance."

Di Lymbury