

Just the Mother

My son was diagnosed with paranoid schizophrenia as a 21-year-old in 1997. Living with him, has at times been horrible and at other times, inspiring. But I am not here, to tell that story.

My message today is to present a list, of what I wish I had known earlier in this Caring role.

This photo-portrait forms a part of a UWA research project. Where I, with five other participants, all Consumers of Mental Health were interviewed over a period of time and had our input coded, analysed and collated into 6 different co-designed educational tools for pre-service medical students.



The photograph, revealing the emotional symbols from my input, was taken in his art studio, and has him behind a veil of transparent black images, where he is in casual, unconcerned observation, as he contemplates his paintbrush. I am standing stoically, appearing trapped in overwhelm, a small, lit candle of hope between us.

Without my son's support, I would not have felt comfortable telling any part of our story or showing any of his images, so, I am proud to share the slides on the screen, as a good way to introduce you to him.

I grew up, with the generational myth of mental health challenges, being founded on the individual's weakness of emotional maturity. That is, if it was related to a female.

If, the challenge was related to a male, the reason was expressed as, a family tendency towards insanity.

Either way, the idea that cause, was the complete story of mental health, are the views which followed me into adulthood, and beyond. My grip on this old idea fractured, when both immediate, and extended members of my family, experienced serious mental health conditions; suicide, psychosis and depression, it was then that I started to feel discomfort, when these episodes were kept a secret or brushed over.

It is no surprise therefore that I found it hard on many levels when he received a Mental Health Diagnosis. Drawing on what I understood from my past, I wanted to know why this had happened to us and who I could blame.

From the beginning, with him fixed in his resistance to understanding or seeking services which could help him, and often, non-compliant with his medication, the relapses which inevitably occurred, were usually severe enough, by the time I was able to get him help, to warrant a hospital stay.

Consequently, as I attempted to make his journey to recovery possible, I had little knowledge to call on. I was, frankly, drowning.

With family and friends finding the seriousness of his illness, difficult to respond to, as “Just the Mother” my feelings of powerlessness and isolation were ever increasing.

All I wanted was a glimpse of “blue-sky”, in relation to his recovery and all he wanted, was to ignore, all of it.

Living in Sydney at the time, I thought a glimpse of this blue sky had appeared when my son expressed an interest in attending The National Art School in Sydney, I readily accepted, that his interest in art and music were for him, more than just an idle activity, and I indulged him with materials he needed. Then, on our return to Perth, he completed a fine arts degree from University of Western Australia.

However, although his girlfriends and other friends supported him during his studies, it was hard for him, and for them, to maintain a connection, following this period of his life. Instead, it was easy for him, in his isolated daily activity to become exposed to the twin addictions of alcohol and gambling.

As our life became more unstable and its negative impact on my ability to manage day to day, became obvious, the unbearable stress, eventually, pushed me towards therapy. It has taken me a long time to work out how to manage my thoughts and emotions, and now, with more skills to set boundaries and better express my needs to him, I have had time to identify events in my life, which have exposed me to the lingering effects of trauma.

With the damage done to my confidence, happening at a young age, I became readily exposed, to seemingly harmless, risk-taking activities.

However, it was the damaging and cumulative effect, from the many unexpected outcomes, from these activities, that was my undoing.

I can see that, in “my end game” of caring for my son, I have had little capacity to manage our situation at home with confidence.

When I first offered my Carer story as a lived experience speaker, I was told, that while many with a diagnosis of a mental health condition, are keen to speak about their challenges, it is rare, for Carers, to speak out.

I can understand their reluctance. Despite the need to gain the trust and respect for the privacy, of the unwell individual, it would be asking too much, of them, to find some clear head space to think. For me, the breakthrough came when, during the UWA research, I was exposed to the likelihood that stigma was contributing to my shame about that unknown something, I must have done, to cause this illness.

It had never occurred to me that anyone would be interested in how my own story, could be so impactful, upon my Caring role, and it has been the act of accepting this possibility that has been, life changing.

Given the time, I have now started to see more clearly what needs to be done to ease those distressing feelings; that overwhelming panic about the need to fix it and my “blue sky” dream about his future. The result has been a calmer, less panicked life.

I am keen to express these thoughts of mine to anyone who will listen.

What I needed was early intervention Carer training, and I needed to hear the truth.

I am not sure who should have had the responsibility of telling me this truth, and I will not deny that it would have been painful.

And, would I have been able to hear it? I don't know if I can answer that question with confidence.

The list of truths I needed to hear, is long, here are a just few of them.

I wish I had been told that when a diagnosis of a mental illness is made, there is an individual who will care about this person, above all others.

They may not refer to themselves as a Carer, but the unwell person needs them. There are a lot of us. We should not be left to flounder. We need to learn new skills.

I wish I had been told that Outreach Services are readily available, but he is the one who must seek them. Just the Mother cannot make that happen. Obviously, many do seek these services, but this has not been my experience. There must be a lot we could learn from those who do achieve connection with these services.

I wish I had been told that recovery means the management of symptoms, finding connections and wellness. It does not mean my "blue sky" view of his future.

I wish I had been told that seeking help, to identify events from my own past, which have caused me to suffer the ongoing effects of trauma, and, being offered strategies on how to reflect upon them, could reveal the impact of trauma on my ability to cope under stress. This would have helped me interpret and understand the context in which we were living.

I wish I had been told that although life will change for all of us, parenting will no longer be enough. Becoming a "Primary Advocate" for the unwell person by developing advocacy through communication and negotiations skills training, may not be for everyone but will better define the work which needs to be done.

I wish I had been told that this diagnosis will impact the lives of all those around my son. They will not easily find an answer as to what part they should play in supporting him.

I wish I had been told that I will worry and be anxious and feel guilt and shame about this diagnosis, and that these emotions, although perfectly normal, should not be left to fester.

I am sure other Carers will have lists of their own. I would love to hear from them.

I have started to work on a project to produce a foundational set of learning outcomes for a training package in advocacy skills. These are the sort of skills specifically designed for those, at home, working as unpaid, Carers, not guided by legal or legislative frameworks, who are floundering as they make it up, day after day.

I hope I can find partners in this pursuit.

A huge thank you to my son for the art he has contributed to this presentation.

Thank you for listening to this message from my story.

Pamela Griffiths

Carer

Contact:

pamelarobingriffiths@gmail.com