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A STORY OF MADNESS

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A Story of Madness, Loss and Reclaiming One Self through the Women's Mental Health Network Victoria: still advocating for women in a changing mental health world.

Mental illness can creep upon anyone anytime. It does not differentiate who it touches. It can be a cruel master who inveigles their way into your life to ultimately murder your soul and leave you a wreck upon the rocks of insanity. For those of us affected by schizophrenia, an enigmatic and sometimes contested condition, it is impossible to explain the isolation one feels when touched by such an extreme life event. The emotions are profoundly raw, and one's sensitivity is heightened where everything impacts on you in a way that is often unbearable and disturbing, and utterly beyond your control. Information floods in unfiltered, creating an inconceivable confusion where doing simple things like having a wash or combing your hair is difficult, or making a simple decision like, will I sit in this chair or that one, impossible. There are times when my head is filled with voices that hurl abuse at me. They hound and harass using insights only they can have. They can be random and rambling one moment, poignant and pointed the next. I do not know where the voices come from, or where they go, why they torment me, and why they are unrelenting in their pursuit of my demise. Often they undermine my friends and the things from which I derive pleasure. And worse, they make me lie to my friends, withhold information; or make me suspicious and mistrustful of them. These voices are as real to me as if I were having a conversation with my friends or if I overheard them talking about me.

Then there are the delusions, the wild, bizzare thoughts that enter my thinking. Often the voices feed the delusions and the delusions feed the voices. Among a plethora of delusions are some that are amusing and many more that are hideously disturbing. I once thought Beethoven had stolen the nine symphonies from me. I was a genius for two glorious weeks! More distressing though was the time when I thought I had been raped by the devil and was carrying his child, the Antichrist. When it was time to go to bed, I feared the Devil was waiting there to rape me again. The terror this struck in my mind was like nothing on this earth and it chills my blood to think of it even now. I was Eve and gave Adam the apple and felt the most acute guilt because I had brought Original Sin into the world. I also thought I had shot the albatross of Coleridge's poem. Bob Hawke was talking to me over the radio telling me to kill myself, which I very nearly did. I have had visual hallucinations of the Virgin Mary and smelt God. I also see a witch in the mirror. Her hair is a tangle of incandescent wire, her eyes are blood red, her teeth are decayed and her face is pock-marked. She stares back at me and mocks me. Psychosis is a nightmare from which you cannot wake. And then there is the deep depression, the dark, black hole into which your thoughts are sucked that often accompanies, or follows, a psychotic episode.

Most of my adult life has been occupied by fighting off my schizophrenia. It has been debilitating and disruptive to the point where I have never had a full time job or done so called 'normal' adult things. Schizophrenia has infantilised me where taking risks, and accepting responsibilities, has not been easy. Some of the collateral damage has been a loss of identity, loss of purpose and meaning, being invisible in the world and a critical loss of hope. Between 1977 and 1991 I had many admissions to Larundel Psychiatric Hospital, a big madhouse which used to be in the outer Melbourne suburb of Bundoora, in which hundreds of patients lived and, in some cases, died. There I witnessed women patients being harrassed by male patients. I was stalked by a male patient in a locked ward from which I could not escape. It was very traumatic. I reported it to the nursing staff but they didn't take my concern seriously thinking it may have been part of my delusional world. On another occasion a male walked into my bedroom naked with his penis erect. I was horrified and scared. Women's lack of safety in public psychiatric settings was an issue I had experienced first hand, so finding my way to The Women's Mental Health Network Victoria (The Network), and becoming a committee member, has been a new chapter in my life. Much of The Network's agenda spoke to my experiences as a female patient in a public psychiatric service.

The Network began in 1988 when a small group of concerned women identified crucial gaps in Victoria's mental health services available to women. They found services were often unsafe with little attention paid to the particular needs of female consumers. These early advocates for change included consumers, carers, mental health workers and interested community members. What was then called 'The Victorian Women and Mental Health Network' was created from their commitment. Within 10 years the Network had already made a submission to the Human Rights and Equal Opportunity Commission National Inquiry into the Human Rights of people with a mental illness, conducted a workshop with Canadian activist Helen Levine (1990), held a forum on sexual assault (1992), drawn up a directory of services to provide women-sensitive services and programmes (1993), held a forum on domestic violence and mental illness (1995), initiated a project for 'Good Practices in Women's Mental Health', and held another forum on the need for women-only respite programmes (1996) and in 1998 published a booklet called *Speaking Out: women's experiences of mental health services* in which women wrote in prose and poetry of their traumatic and terrifying encounters with public psychiatric hospital wards.

When the Network was formed in 1988 psychiatric services were mostly delivered in the big stand alone psychiatric hospitals such as Larundel, Mont Park, Plenty and Royal Park. The spectre of these Dickensian madhouses had long haunted the psychiatric world with myriad horror stories being told by survivors of abuse and coercion, and of long incarcerations where people, who had become institutionalised, were locked away and mostly forgotten. These old institutions used to have single sex wards until the mid 1960s

when it was thought that if women and men were integrated in the wards the presence of the women would ameliorate the men's behaviour and help to socialise them. From then on the wards were shared by men and women. Many women, like me, struggled in these mixed wards often having to suffer the uninvited attention of abusive male inmates. Women who may already have had a history of childhood sexual, physical and emotional abuse suddenly found themselves being re-traumatised in a place that was supposed to be looking after them. The Network was the one organisation that dedicated its work to helping to raise awareness and bring about better services to make public wards safer for women consumers. The forums and publications of the 1990s had all identified the perilous situations women faced when admitted to a psychiatric ward.

I joined the Network in about 2006 just before it published another booklet called *Nowhere to be Safe: women's experiences of mixed-sex psychiatric wards* in 2007 in which it reported the following:

In 2006 we surveyed 75 women consumers, of whom 61 per cent had experienced harassment or abuse in hospital. 51.5 per cent of these women said that they would prefer women only wards and a further 27 per cent identified a need for more separate sleeping and recreation areas. We also surveyed 42 mental health staff of whom 70 per cent reported that harassment and abuse occurs in wards, 30 per cent saying it occurs 'frequently'. This is especially alarming given that 50 to 70 per cent of women inpatients have experienced past physical or sexual abuse, including child sexual assault. ¹

This report confirmed the earlier work of the Network that had identified women's safety in psychiatric wards is an issue that had to be addressed by those who designed psychiatric facilities. And while the mental health world has changed radically since 1988 - the stand alone psychiatric hospitals are long gone, consumers no longer spend months and years in institutions, fewer NGOs deliver services and a new Mental Health Act in 2014 that shifted the focus onto consumers and their human rights – women are still vulnerable in psychiatric services. Disturbingly the issues facing women consumers remained similar to those that were identified when The Network was first formed in 1988 and were comparable to what I had experienced as far back as 1977 in Larundel. And sadly even though the old hospitals are long gone and new psychiatric wards have been attached to the general hospitals, women are still overwhelmingly unsafe.

27 years on, and with a new name, The Women's Mental Health Network Victoria is still advocating for women consumers in a vastly changed and changing mental health world. We have successfully lobbied state government to introduce women's-only corridors in public psychiatric wards and advocated for separate bathrooms. The Network has developed a Gender Sensitive Training package for workers based on a wide consultation with stakeholders, including CALD and LGBTI representatives and a strong

consumer contingent. Funded by the Department of Health, the modules were rolled out across Victoria in partnership with the Centre for Psychiatric Nursing. The Network holds the licence for the package, including its capacity for train-the-trainer. We have also developed two innovative programmes - *Women Speak Out* and *Breaking the Silence* - both aimed at empowering women with the confidence and skills necessary to tell their stories to different audiences. Both programmes aim to help women feel confident enough to engage with an audience, sit on committees, take part in conferences and advocate for themselves. *Breaking the Silence* has another component which is to help women in rural and regional areas make connections with each other and have ongoing communication.

I had initially started telling *my* story through the medium of poetry. From the early days I had been documenting my madness in poetry and after some time, when I had enough poems for a collection, Spinifex Press published *Poems from the Madhouse* in 1993. And with that my life was transformed. Suddenly I had an identity I was comfortable with, that of 'poet'. And seven other books have followed including a memoir *Flying with Paper Wings: Reflections on Living with Madness*. In my poetry I seek to move angels to tears and make a stern God laugh. Story-telling helped me to rewrite my life simply by giving me some meaning and purpose and restoring hope. It gave me a reason to get out of bed. I knew deep down where my spirit meets my bones I was more than my label 'schizophrenia'. I have been a public loony for some years now and I have experienced the validation and affirmation that one can get from sharing one's story with an audience. My aim is to raise compassion, respect and understanding for my mad comrades. Story-telling is a commanding medium and one of our committee members, Jude Stamp, a great story-teller herself, has written that:

*"No-one can tell their story like the woman who has lived it. And when she finds the support and courage to share it, everyone wins: the woman herself and all those she trusts to provide safe and gender-sensitive services. That is how powerful women make a powerful difference across the whole mental health system. And, it's up to all of us to hear the consumer voice, learn from it and act on it."*²

The evaluation of *Breaking the Silence* was mainly positive with one woman saying:

*"Well for me I actually looked forward to the women's group every week. To me it was something that I needed to do I think. I enjoyed listening to others; working out my strengths and all that sort of stuff. So for me I came out of it a lot better than what I went in."*³

The Network was also actively engaged with the 2015 Royal Commission into Family Violence first holding a forum to gather the stories of women affected by mental illness

and family violence and then by making a submission. The forum was a powerful and important event which uncovered the often tragic and harrowing circumstances many women faced with violent partners while living with a mental illness. The submission said the following:

The Network's consumers raised concerns about how women experience disadvantage because of the broken mental health system with the lack of coordination between the mental health and family violence sectors being one of the contributing factors. The notion that women can be trapped in a toxic relationship because of poverty, threats of homelessness, children to look after, emotional abuse and the like, and if the woman has a diagnosis of mental illness, can exacerbate the entrapment through a dependence and fear she is saddled with, because she cannot access appropriate services. ⁴

One of the women who attended the forum reported a common problem many women who live with a mental illness and family violence face:

"I called police to report violence they said I had mental illness so they would have to call the clinic to ask for proof I was credible." ⁵

While the submission was one of many the Royal Commission received, ours demonstrated that The Network is still advocating for women with a lived experience of mental illness and the obstacles they face to live meaningful, happy and safe lives.

My involvement with The Network has been challenging and rewarding. Challenging because I have been taken out of my comfort zone on many occasions in having to engage with policy work, make decisions, take responsibilities and be an active member. In recognising my strengths and attributes I have also identified my weaknesses. Through committee work there is an imperative to be a team member and to put aside one's individual needs to advocate for a common purpose. My story is not one of overcoming a mental illness but of living within its constraints and doing the best that I can. And while making decisions and taking responsibility don't come naturally to me, working with The Network and being supported by its members, has helped me to nurture new skills I didn't think I had. Feeling valued and having a voice has helped to break the chains of invisibility that had shackled me to the shadows of the nether world.

The Network committee is a collection of consumers and workers in various fields, and together we listen to, and hear, the stories of women who at some time find themselves using psychiatric services. It continues to focus on women who live with mental illnesses seeking to understand their experiences and ultimately advocate government and services to be sensitive to their needs and give appropriate care where needed.

How best to make them safe and how best to empower them is what we at the Women's Mental Health Network Victoria try to achieve. I would not want women to have to feel as powerless and fearful as I have felt in the past in a psychiatric ward; no woman should ever feel unsafe while in care. The Network has been a strong influence in advocating for women for 26 eventful years. And in being part of this dynamic group I have found my own voice and raised it too.

References:

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4. Women's Mental Health Network Victoria. (2016). Submission to the Royal Commission into Family Violence, p. 6 (see www.rcfv.com.au).
5. Ibid p. 7