

# Complex post-traumatic stress disorder—breaking the silence of the fringe dweller

## Jacqueline King<sup>1</sup>

<sup>1</sup>glass artist, sculptor, mother, survivor

*A personal account of experiencing complex post-traumatic stress disorder in regional Australia, its effects on the sufferer and the benefits of an arts practice to the long-term management of PTSD, plus how sufferers fall through the cracks of support from medical staff, government and the arts industry largely due to lack of awareness of this debilitating illness.*

Hi, my name is Jacqueline King and my paper is titled 'Complex PTSD—breaking the silence of the fringe dweller'. I used this title as I am a fringe dweller in every sense of the term.

I'm a fringe dweller because I am an artist, because I live in regional Australia, because I am a single mum, because I am a survivor of childhood sexual assault and I talk about it, because I suffered bullying, sexual harassment and sexual assault despite being a senior executive, because I suffer a diagnosed mental illness, because I cannot now work in paid employment, because I suffer complex post-traumatic stress disorder, because until just recently I was unable to claim disability support payment as they said it was a 'treatable' illness but if I had depression it would be approved, because CPTSD is not yet listed as a separate diagnosis in the DSM-V (*Diagnostic and Statistical Manual of Mental Disorders*).

The traumas that lead to my diagnosis are not meaningful to this discussion as all traumas are by definition traumatic and therefore comparison is futile.

My greatest hope is that speaking about my own experience of CPTSD and the journey since diagnosis will allow courage to rise in the many others who also suffer the grip of this isolating and misunderstood condition ... to allow health practitioners a glimpse into what it is like for a sufferer and if only one other can have an easier journey to healing via the illumination of my story, I will have succeeded.

Of course you can all go and read about it online or in books and journals but if someone stands up and talks about it and they've lived it ... well, the understanding is surely more potent as I am a person, not a patient!

So let's get to the definitions ...

### **What is post-traumatic stress disorder?**

PTSD is a severe anxiety disorder that can develop after exposure to an event which results in psychological trauma. This event may involve the threat of death to oneself or to someone else, or to one's own or someone else's physical, sexual, or psychological integrity, overwhelming the individual's ability to cope. The trauma causes an over-reactive adrenaline response, which creates deep neurological patterns in the brain and biochemical changes in the brain and body that make it differ from other psychiatric disorders.

Formal diagnostic criteria require that the symptoms last more than one month and cause significant impairment in social, occupational, or other important areas of functioning.

### **What are the symptoms of PTSD?**

- Intrusive thoughts—persistent re-experiencing, flashbacks, nightmares, rumination.
- Avoidance/numbing—of stimuli, people, places, smells, sleep, inability to recall major parts of the trauma, decreased capacity to feel certain things.

- Hyper-vigilance—increased startle response, difficulty falling or staying asleep, problems with anger or irritability, panic attacks, memory and concentration problems.
- Symptoms persist longer than 30 days and create clinically significant distress or impairment.

### **What is complex PTSD?**

The traumatic events connected to complex PTSD are long-lasting and generally involve some form of physical or emotional captivity, such as childhood sexual and/or physical abuse, domestic violence or captivity as prisoner of war or hostage, also continual contact with natural or human disasters.

In these types of events, it is common that a victim is under the control of another person of significance and does not have the ability to easily escape.

Symptoms include:

- emotion regulation problems—chronic sadness, suicidal ideation, irritability, hidden or explosive anger, fear
- changes in consciousness—dissociation, memory loss, repressing, suppressing or reliving trauma
- changes in how a person views themselves—shame, helplessness, self-loathing, lack of trust, feeling ‘different’ to others
- changes in how the victim views the perpetrator—isolating, looking for a rescuer and/or mistrust. People with CPTSD may view the perpetrator as all powerful or be obsessed with the relationship which may be accompanied by thoughts of revenge.
- changes in personal relationships—pervasive insecure attachment
- changes in how one views the world—despair, loss of hope, suicidal ideation.

Complex PTSD does not yet have a formal place in the DSM V as 92% of sufferers also fell into the diagnostic parameters of PTSD. The condition however is in my lived experience more entrenched and harder to heal due to its complexity in source traumas and resultant identity destabilisation.

### **Ok what does all that really mean in laymen’s terms?**

I became a sleep deprived, hyper-stressed, hyper vigilant, panic disordered mess who couldn’t read, write, spell, articulate what the problem was or function in any normal way. I couldn’t go to the shops, answer the phone, maintain significant relationships, remember appointments or more often remember anything at all.

If I’d write lists I’d forget where they were. I’d wake up screaming each night. I’d suffer panic attacks and think I was dying. I couldn’t articulate what I was thinking as if I had been rendered mute or dumb. I couldn’t sit still, I couldn’t sleep, I couldn’t find peace whatever I did or wherever I was. Everyone and everything was scary and overwhelming. I had frequent suicidal ideation.

I couldn’t play scrabble ...

(Laughter is a great healer and I’ve learned to laugh with great compassion at my own weaknesses that are the hallmarks of CPTSD and the result of surviving traumas)

I have not been able to maintain paid employment since 2006 despite several attempts to do so ...

Why? I have learned what some of my triggers are ...

For someone with PTSD/CPTSD the world can be full of triggers. 'Triggers' produce a cellular memory of the trauma and for the survivor make the source of traumas feel very real and present again despite rational evidence to the contrary.

Mine involve authority figures/institutions, power disparity, abuse of power, not being listened to, not being believed, Chryslers or white Holden Statesman cars, being held too tight or restrained in any way, being paid by an employer (that's a tricky one to manage and keep feeding the family as volunteer work doesn't pay well), chardonnay, office products and bald men just to name the known ones ... oh and public speaking!

### **Art as therapy**

I heard recently an interview with a leading UK trauma psychiatrist who described PTSD something like this ...

"Imagine you are a beautiful hand blown glass vase with exquisite colour and form sitting on a sideboard and much admired. When major trauma happens the beautiful glass vase that you are gets knocked off the table and smashes on the floor splintering into thousands of pieces. Most rush quickly to gather the pieces and try valiantly to hold it all together, to appear like they used to be by holding all the pieces together with anything they can. But there is no way to do this of course.

Some, with good therapeutic support coupled with the support of loving family and community, will slowly learn that there is no becoming what they were ... but they just might become a beautiful mosaic instead!"

I like that metaphor ... especially as I now find myself a practising glass artist and sculptor.

I came to glass as a form of therapy and never having showed any meaningful creative talent in the past.

It taught me to breath, to be still, to develop patience, to see beauty in and around me. It offered me peace and meditation, a sense of the power of the present moment. It ultimately became my obsession and my salvation.

It helped build new brain synapse connections necessary for healing after a brain injury ... and I can assure you chronic CPTSD is a brain injury in every way.

The building of these new neural pathways was exhausting, as they are for new borns learning to interact with the world and use their bodies, or those with ABIs (ABIs are acquired brain injury—traditionally attributed to a physical cause like an accident, injury or stroke).

Frequent sleep and high level nurturing is required during this re-mapping or else frustration and exhaustion can become overwhelming and lead to emotional fatigue and outbursts. But determination by survivors and their supporters to map new brain pathways is invaluable to the ongoing effective management of complex PTSD and recovery from the darkest trauma.

My arts practice offered playfulness, imagination, colour and ultimately the reformation of a new identity, a new me ... a mosaic from all the shattered parts of me ... from business executive to glass artist who is even brave enough now to speak as an advocate for others with CPTSD.

### **What are the challenges in rural and remote areas? (anecdotal experience)**

- Public understanding or knowledge of the condition is poor.
- Social stigmatisation can be worse as social networks are often tighter and the destabilisation of mental illness even more unsettling and shame inducing.
- Information about available services is sparse.

- It is more challenging to find expert therapeutic help (Psychologist with trauma specialisation) within any reasonable distance.
- The best facilities are capital city based and very costly (e.g. St John of God—Sydney residential program for PTSD treatment).
- Government departments are not trained to respond appropriately. Centrelink is a case in point where I was told by a Job Capacity Assessor early on in my journey that PTSD was treatable and not eligible for DSS unless depression was present and therefore I had to meet with an unknown and changeable person (usually a man) from an employment agency each month as a minimum to get any assistance and avoidance would not help me ... she knew cause she was a psychology student. I went home with my support person in shock and tears and didn't try again for years.
- Employers/agencies are not educated or trained or often willing to manage sufferers.
- No support groups available to assist in the inherent isolation felt with CPTSD.
- GP response is not adequate with very short consultations, poor training on mental illness support and strongly weighted towards drug control.
- Psychiatric response where available is usually very strongly weighted towards drug control and has inherent dangers of misdiagnosis with dissociative identity disorder, personality disorder, generalised anxiety disorder, disorders of extreme stress not otherwise specified, or even bipolar disorder having blurred boundaries to CPTSD and if misdiagnosed the condition can become entrenched and mistreated (remembering that PTSD and CPTSD are, in my lived experience and rationality, normal responses to abnormal life events where healing the traumas can only be achieved by slowly processing them mentally and physically, witnessing of the trauma by loving supportive family or friends, expert trauma therapy, and slow release via physical/spiritual/art therapy with a great deal of care ... but never by pathology).

### **What a public education campaign might deliver to sufferers**

Perhaps most importantly the condition might be recognised earlier and better identified by sufferers or those within their circle and therefore treatment might be sought before secondary traumas occur from loss of employment, damage to significant relationships, drug and alcohol problems, possible incarceration or even suicide.

If a sufferer is employed at the time of diagnosis the employer might be better prepared to assist their staff member with practical assistance (extended leave with and without pay) assisted re-entry to the workforce in a manner adapted to the condition, compassion and avoidant of any stigmatisation. As has been the groundswell of action and awareness around depression via Beyond Blue, this should be possible for PTSD/CPTSD.

When triggers occur and the condition re-ignites all the worst symptoms immediately post-trauma become present again as if the traumas were recurring in the here and now. Subsequently concentration, reading and writing and interacting with strangers and even loved ones all largely evaporate. Hyper-vigilance and fear become all pervasive and sleep evaporates. Self-loathing, nightmares and even suicidal ideation and despair can recur.

This can come out of the blue and often with an unknown or previously unrecognised trigger leaving not only the sufferer but those around them dazed and confused. If this happens to coincide with an important event or meeting or in my case as a visual artist with a pending exhibition, grant submission, applications of any kind or dealing with the public, the outcomes are ... well ... shall we say ... less than ideal. Creative output can suffer or become manic and unfocused.

Relationships suffer, including personal and business contacts made along the way.

People can lose trust and faith in you, misreading your responses as incompetence, laziness or just, dare I say it ... 'crazy' by not recognising your responses as being PTSD related.

If society at large, those within the social circles of sufferers and sufferers themselves can identify the behaviours inherent to PTSD/CPTSD as attached to the condition which is an understandable response to extreme trauma that was out of the control of the sufferer then it can alter the emotional response. Compassion can come into play rather than confused judgement

### **Sustainable healing**

To achieve any sustainable healing for sufferers of CPTSD/PTSD I propose the following:

- Public knowledge and understanding needs improving.
- GP awareness, involvement and ownership of health outcomes improved.
- The condition needs recognition and inclusion within the framework of disability support and assistance given where possible as it is for others with disability (e.g. advocacy in liaising with institutions, gaining assistance, health care, day to day care, family relationship assistance, government assistance with costs of therapy, employer support and education to encourage re-employment outcomes etc).
- Understanding and compassion applied when sufferers are hit with symptoms and their responses alter via additional personal assistance, time out space, extended allowance for stress leave etc.
- Sufferers need and deserve advocacy and ultimately the courage to stand up and be counted and stand together in mutual support.

The National Rural Health Conference inviting me to speak as a survivor is a brilliant start ... THANK YOU!

Post script: The good news after nearly 8 years I am now receiving support from Centrelink under DSS. They finally accepted the diagnosis of chronic CPTSD without the additional tag of depression, and my arts practice is not treated by them as an impediment to this and a sign I am work ready, but rather as a therapy, truly lifesaving in its daily practice, which is what it is.

I have made it through nearly 8 years without drug therapy (an important milestone for me—but not all sufferers share this view). I do not smoke tobacco or drink alcohol any more after discovering more recently that I was using them as justifiable coping mechanisms but they weren't actually helping me cope. So I went cold turkey ... and that's a whole other story ...

Needless to say in order to cope with the torrential emotions present with being a survivor without self-medicating I must practice mindfulness on a daily basis to stay grounded in the present (which by the way is a free therapy, easily taught and available to all regardless of location) and each day my glass work keeps me safe and with hope for another day.

I remain in regular therapy under a mental health plan with a great therapist.

It is never over ...