



"THE LONG TERM IMPACT OF CHRONIC DISEASE ON MENTAL HEALTH"

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I'm a mom to Juan (aged 10) diagnosed with Pompe Disease at 11 months old, the Continuous Traumatic Stress disorder that comes with living with chronic illness is a real challenge.

At first, I couldn't quite identify with the fact that I was developing severe anxiety. Between being a first-time mom, pregnant with my second child, and now having been thrown into the unknown world of rare diseases, it was only natural to feel overwhelmed, right?

As time went by and days became months, which turned into years life took a completely different path to the white picket fence picture I'd initially imagined. I had a sick child. The thought of death followed us around like a dark cloud, and every morning I would wake up with the trepidation of that day possibly being the last for my blond haired, green eyed boy.

It was only about five years later, upon having called up my husband and berating him for removing a handheld drill from our tool box, that I realised there might be a problem. You see, I was living on

adrenaline, I was always waiting for something to go wrong, and I had started seeking problems that MIGHT happen. I had become completely and utterly controlling.

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Sleep had also faded into a distant memory and getting up every 30 minutes to check on my son had become routine. If you'd asked me then if I was depressed, I'd have answered a definitive no, because symptoms of depression are generally apathy, excessive sleeping, and loss of interest etc. I had none of those. I was up and about, over busy in fact, I wasn't sleeping at all and had become hugely passionate about rare diseases, to the point that it was

all I thought about. And therein lay the problem.

PTSD is generally related to a single event, while CTSD is related to a series of events, or one prolonged event. This is a relatively new concept, and due to its variable nature, it may often be diagnosed as Borderline Personality disorder.

Trauma has extreme and potentially devastating effects on emotional health, especially when it lasts a long time. People who are exposed to danger repeatedly or for a long time may develop continuous traumatic stress disorder (CTSD) as a response.

CTSD starts off as the body's natural response to stress. Cortisol, endorphins and adrenaline all work together to get the body to avoid danger as part of the fight or flight response. In 1986, South African writer Frank Chikane first used the term CTSD as he explored how apartheid affected a generation of children.

In adults, the long term effects of CTSD can include:

- Learning disabilities
- Panic attacks



- Dissociative disorders
- General sickness and immune deficiency
- Violent and impulsive behaviour
- Insomnia
- Substance abuse and addiction later in life.

Symptoms for children are similar but also include behavioural problems, poor impulse control, pathological self-soothing (through dysfunctional coping mechanism such as self-cutting).

Taking the above into account, it soon became clear that there was an evident medical issue needing to be addressed with myself, but also, that of my son and the rest of our immediate family. The reality was that we lived with the trauma of continuous, repetitive, life-threatening events in the form of seizures and cardiac arrests alongside complex medical procedures and invasive therapies. Basically we were living in a medical warzone, and the long-term impact of the continuous battles being fought had taken their toll.

As a family, we immediately sought medical support and started therapy to provide us with appropriate coping mechanisms. We also ensured my son received formal emotional support and discussed methods of reducing the impact of the traumatic medical events with our medical team.

Four years later I remain on medication but we have managed to wean my son (now aged 10) off all anti-depressants. He continues to take medication for concentration and memory. He no longer battles with insomnia and has integrated well into a mainstream school with educational support, and is thriving, despite living with a life-limiting disease.

I continue to be reliant on

medication for insomnia, and anti-anxiety medication remains a critical survival skill. But we're at least now aware of the impact and manage the symptoms accordingly.

As a mom to a CTSD patient, and being a CTSD patient, I would highly recommend that all clinicians dealing with any patients impacted by chronic illness complete mental health assessments on their patients. A survey report by Rare Diseases South Africa on a sample group of over 300 rare disease patients indicated that over 90% had never been evaluated for anxiety or depression.

Every one of these patients fights a battle within their bodies every day. Without mental health support, we're sending them to war without ammunition.

QUESTIONS YOU CAN ASK YOUR PATIENTS/CAREGIVERS TO DETERMINE IF THEY NEED ADDITIONAL SUPPORT?

Don't ask standard questions, they need to be framed in a different way to truly ascertain the need for additional support. We once

had a patient being evaluated for a neuromuscular disease. The question asked was "Do you battle to walk up stairs? The answer was no. But after exploring the question further, it was determined the patient had been avoiding stairs for years due to extreme pain, and therefore whilst her immediate answer was correct, it wasn't framed correctly when asked.

1. When last did you wake up feeling refreshed and rejuvenated?
2. Is your short-term memory the same as it was before being impacted by chronic illness?
3. Are you able to fall asleep reasonably easily?
4. Do you find yourself being overly irritable or having anger outbursts?
5. Do you have difficulty concentrating?
6. Do you startle very easily?
7. Are your senses heightened?
8. Do you find yourself obsessing about minor details on a regular basis? **MHM**

References available upon request

