## Royal Commission Into The Mental Health System, Victoria

### Monday 29 April 2019 at 4.57pm

## PART ONE The Overview

Innocently taking one tablet daily, too physically fatigued and physically weak compared to my regular self to ask any questions willy nilly regarding what I am supposed to expect from Eleva, Zoloft or Efexor. At the time I am told few details in the appointment. I received no diagnosis in the sessions, by post, by documentation. Can it be some sort of psychiatry assertiveness test to assess my self awareness and external awareness. I am too fatigued, drained, overwhelmed, not by the poor quality or the amount of details into anything psychiatric, administrative or anything at all. Rather I am noticing that the room is very poorly lit, the consultation is quiet, too little discussion, and the psychiatrist is still, silent, unmoving physically and the consulting office is bare, non descript and boring.

Current day. The mind is not shattered from memories. The mind is devoid of the memory recall, incapable of holding, storing and retaining memory and details in the short-, medium- and long-term. The medications' effects are serious, such that the mind is blank all of the time.

Heat regulation of the body in the heat and the cold is dangerous. I heat up fast and stay heated and overheated for too long. I am even in Melbourne's autumn cold.

Psychiatric medication, of which I am being prescribed and I have administered and I have been on for around fifteen years, is replete with problems for me.

Timelines and timeframes merge and conflate as the medication is strong, over prescribed, consequently causing headaches, migraines, eye headaches consisting of sharp, stabbing, lengthy pain in the own two eyes, poor memory retention, storing and recall, confusion, weight gain and obesity, slow speech, rigid bones and rigid, stiff muscles, high blood pressure, difficulties in undertaking basic and necessary cleanliness routines including but not limited to showering, bathing and wiping the water over the torso. Passing urine and the own faecal matter by sitting on the toilet seat is not at all possible; I have few physical choices while I use the toilet, and I grip onto the brickwork wall as I am bending my knees and I hover well over the seat and the rim of the toilet bowl. Comparably sitting on regular height chairs, seats and couches is not possible. Over the bathroom sink I wash my hair and the aching bodily

back spine and leg pain increases. I cannot bend my back and legs to sit on the bathroom seat anymore after taking the prescribed Risperidone and the several months' prescription of Abilify Maintena injections. I am experiencing no enthusiasm at being injected with Abilify Maintena. At the first mention of the Abilify Maintena injections I drew up the blank. I had never heard of the term 'the 'depot', I knew not anything whatsoever about injections, and I lacked familiarity with the Abilify Maintena, having not heard of the medication in my life. The treating team who are the psychiatrists and the registered psychiatric nurse did not assist me by introducing and expanding on the new knowledge of the Abilify Maintena. At the time I was under no illusion that the Abilify Maintena could be 'weight neutral' or slightly weight inducing as the many prior medications had the opposite effect. I felt shocked and the alarm set in as I was shortly injected with the Abilify Maintena.

Upon injection of the Abilify Maintena I immediately felt the stinging and the aching pain at the site on the high forearm, which lasts for around the seven day week with each injection. Additionally the mind soon became blank, vacant and numb. My body felt heavy with the influenza like ache all over.

For every day on the injections aforementioned I can feel noticeable pain, the flight or fight anticipation and response is blocked, little that it was before the injections while I took Risperidone and the Abilify tablets. I feel that I have the nasal congestion daily and the frustrating runny nose each day. I suffer from the ongoing voluminous diarrhea, similarly each day. Instead of perhaps excreting faeces once a day in the morning as I used to on the Abilify tablets 10mg I go at least thrice daily and each time the texture is thick and sludgy or drippy and watery, and frequently both textures in the one toilet occasion are present. The faeces are odorous, stinky, and the food is not fully digested in the bowel motions despite chewing on many food items.

Hair thinning, losing hair on my brush and in the shower, when it was possible, throwing out tiny spirals of my wavy hair in the rubbish bin are affects of any of the medications. I am thirty-eight years old and I do not have cancer, I have never undergone chemotherapy, radiation therapy and cancer treatment.

Purple lips cracked. Freezing, chilled and shivering, in my own queen size bed is not what I want. No concept of how cold that I can ever feel in late April 2019 Melbourne.

Purple lips cracked. Back and spine stiff and near rigid. No, is what I think they deserve. No, is my instinctive thought and feeling, and my experienced resolution and response to the ongoing prescribed medications. No, is what I want to voice aloud, in the face of the medications that hold, halt, curtail, reduce, ameliorate, and regulate the Schizophrenia.

I have not received, been relayed and communicated the detailed face-to-face assessment of the diagnosis, the analysis and the prognosis by the psychiatric practitioners. The over prescription of medication for years is continuing. The injections of the substance A and B combined into the

muscles of my own arm near to the shoulder bone is unacceptable and the injections provide pain rather than relief. I sit dazed and sore. I am not suffering from psychosis and for many years I have not had any psychotic episode. The response by Victorian mental health to inject the Abilify Maintena as I took myself off the Abilify tablets for around four months, subsequently relieving myself of the anaphylactic nausea, vomiting, itching and overheating is the decision that I made by myself. The frustrating, distracting and debilitating itching happened on many parts of my skin including on the genitalia. The itching continued at any time of the day. I stopped the Abilify tablets abruptly and I know that the itching that occurred for the serious lengthy time lessened and ceased.

No, I do not want to be obese from healthy eating and restrictive eating, and I do not want to stop moving. No, I do not want to be contained in my parent's house for months on end while I am obese and dangerously overweight. I cannot now physically accompany my mum and dad anywhere in their cars to any event, activity and duty. I expect to spend my thirty-eighth birthday at home and hopefully I will not be confined to my own bed.

From the minimal detailed hospital reports that I have read I reach the idea that I am severely mentally unwell. The reports suggest, infer and they state that I must be the partially self unaware, disconnected from reality, socially withdrawn, individually withdrawn, and hostile overweight woman, among other symptoms and qualities.

The homelessness of which I went through and I experienced off the Abilify tablets medication in the self aware, non itching state, and with which I shed around only five kilos is the event that I at least know is the temporary relief for me. The homelessness offered relief from the ongoing prescriptions, and if anyone conceives of the burden of carrying in excess of thirty extra or so kilos at the time, the feelings of being alive and of feeling actual emotions returned gradually. I also was able to move outside of the parent's home.

No, I am physically ill at the moment and I have been physically ill from the re commencement of psychiatric medication treatment. I shunt my body around on my two thickly, heavily set legs, which are physically weak. The nausea commenced. The dry retching and the vomiting commenced. The other side effects being on any medication started.

The shunting that I saw and I observed in passers' by as the innocent and naïve bystander and judger of strangers as the obese mentally ill makes me cold to this day. I judged some obese, slow to move individuals as mentally ill and discriminated in my mind against the obese and the mentally ill. Experiencing the obesity caused by the psychiatric medications shocked me into the realisation and the recognition that one can do more than observe, judge and discriminate. Obesity in the psychiatrically medicated is potentially caused by the high sedation and the metabolic effects of psychiatric medication on the human body. The effect on the central nervous system of many of the psychiatric medications, that being the slow down of gait and of other movement and the tendency to increase weight retention all over the

body is the damning inheritance of psychiatry. The atrocious over forty kilos of weight gain onto every area of my body specifically on the gut, the feet, the neck, the spine, the inner upper thighs near the female pelvic bones and on the ankles is worsening the longer that I am medicated. I fear that the weight gain and the obesity is to continue.

A system that leaves me powerless, stuck in limbo, silenced and obese, and which does not permit multi factorial techniques and theories of the human mind, is lacking in psychiatry.

I compose from my own bed, from the heart, lying down on the side of the own body frame. Since the mind on the medication Abilify Maintena is damaged the whole body limits are many and problematic.

My mind is not what I can call shattered. In fact I do not know what 'shattered' is. Might I say is that the regular frailties of the human body physically and the body internal systems are individual and idiosyncratic. It is difficult to prove to psychiatry and as the non medicine qualified, trained and practiced individual from a family of non medicine people is akin to the blind leading the blind. I know not what to say to any psychiatrist and psychiatric nurse regarding what is normal for one's own body as one is presented with one tablet and told to swallow with water. Thence my lack of confidence in 'pill popping' is one of the reasons that I do not advocate a one size fits all system.

# PART TWO Prose

Efexor, Eleva, Zoloft. In the start. I stare in the mirror and look at my pupils. I do not understand what I can tell the own psychiatrist. With regards to the eyes changing. They are changing. In under one minute. The pupil area is big. Then reduces. The same pattern repeats. Focusing is the trouble. The eyes take longer to adjust in all light. Dim light is the serious issue as I can make out objects slowly.

I stride with purpose. To work. To the train station. To the shops. I exercise. Back then I pace at home. I believe restless legs syndrome was discrete and different. Not what I had. I skip tablets accidentally and for under one month. Psychiatry. I am apprehensive. A medication can possibly assist in raising my deflated mood and my low energy levels. Before I take any tablet at all I think that I am far too lethargic to work. I fall ill with gastroenteritis. Dry retching is the usual. Commonplace in the morning. On eating breakfast. On brushing my teeth with toothpaste.

Later, Abilify 15mg. My schizophrenia worse as the psychiatrist says, as I was led to believe. Upon the increase by 5mg. I was under the impression that 'doctor knows best.' I accept my diagnosis of schizophrenia. Because why

would I know otherwise. The generic text book definition and explanation of the positive and the negative symptoms. Frighten me on paper. I am despondent, sad and bewildered. At the language and the categories. I guess I am that, like that. Schizophrenia is an umbrella term I guess. Schizophrenia is related to poor vitamin D levels, social withdrawal, partial disconnection from reality, paranoia and few friends. Years later I am told the details that there are positive and negative symptoms. I am uncurious and un nosey anyway. The confusion of categories. I am living and I change my life to fit in with the medication and psychiatric appointments. The new knowledge founded is bare. Psycho social education is good. Distracting. I am uncertain what I am to take from anything psycho social. I am interested. I am easy going. I do not appear sedated strongly. In hindsight I never come to grips with the positive and the negative symptoms. Pertaining to anaphylaxis I do not know that psychiatric patients can be in anaphylaxis.

I suppose that I have anxiety. I feel stressed more on the medication Abilify tablets. One afternoon I sat crying in the lounge room at my parent's house. Where I live. The crying grows into feeling asphyxiated. The own throat tightens. The panic attack feels dangerous. I can only breathe. The own throat narrows. I am stressing.

I know that I am struggling. I do not work with pay. I volunteer. Several hours each week. My aspirations are unfulfilled. I have put my ambitions to the background. I make my goal to work again. Employed. Is the new life. I am bored and I feel guilt at reading during the day. I used to envisage myself with a new car. A partner. Working.

Duties like reading a little in the newspaper, cooking, required and non required meals, and exercising. Going out with friends.

I think full time and part time work is the ideal. I am childless and I am single. My life is delayed. The options are fewer: I am too tired to study, I am poor, my friends who study are onto their postgraduate courses. They are in relationships. Or married. I require change. I pride myself on my mind healing. Others who I encounter look overweight, out of it, talk slow, dress unlike anyone who I know. I am ok. Anaphylaxis means the tightening of the throat to me. I get the respiratory illness and the rotten viral infections. I take the antibiotics. Prescribed for the full courses. On top of the psychiatric oral medications. I feel muscle aches. I feel dizzy. I have diarrhea. Severe.

Gastoenteritis as I work full time. I have bowel movements that smell odorous. The drippy diarrhea passes out of me quickly. All out. I am pale and physically weak. Occasionally, I vomit while I have the gastro. I lie in bed. For much of the day. I do hardly anything. I read the paper. I take time off from working with the gastro.

I wind up spending as little as all the disposable income. Waking at six o'clock am and it is usually still night. Really. An hour is the duration I allot to prepare for the departure. Medication. Eat. Porridge. Shower. Dress. No make up. I am in the youth, and additionally I am wary of clogging the face skin. I am too

squeezed for time. I am lethargic. I exercise informally by walking in office shoes. Heels are easy to walk in.

I continue to take the half hour exercise bike regime seriously. Not even the handful of occasions each week.

Skip to the present day. I am obese as the weight body scales and the BMI or the body mass index estimate. The medication that I am on after withdrawing from the Abilify tablets causes ravenous appetite cravings, weak taste sensations on eating any food and drink.

I sometimes feel that I am gorging myself. The empty gut looks full and distended. I have little motivation for anything. The eyes are extremely dry. My pupil size changes – the pupils are small. I overheat and I develop fevers. Underheating and chills. The medication impairs my own judgment; confusion, severe memory lapses, almost no memory retention and similarly, no memory recall.

While I am not accessing and utilising the hand walking frame and the wheelchair I do not have the physical capacity to pass urine sitting. The back spine is near rigid.

### 2019 Submission - Royal Commission into Victoria's Mental Health System

#### **Organisation Name**

N/A

#### Name

Ms Suzanne Fiona Knight

What are your suggestions to improve the Victorian communitys understanding of mental illness and reduce stigma and discrimination?

The suggestion mainly is to provide detailed information with regards to the meaning of different mental health diseases.

What is already working well and what can be done better to prevent mental illness and to support people to get early treatment and support?

N/A

What is already working well and what can be done better to prevent suicide? N/A

What makes it hard for people to experience good mental health and what can be done to improve this? This may include how people find, access and experience mental health treatment and support and how services link with each other.

N/A

What are the drivers behind some communities in Victoria experiencing poorer mental health outcomes and what needs to be done to address this?

N/A

What are the needs of family members and carers and what can be done better to support them?

N/A

What can be done to attract, retain and better support the mental health workforce, including peer support workers?

N/A

What are the opportunities in the Victorian community for people living with mental illness to improve their social and economic participation, and what needs to be done to realise these opportunities?

N/A

Thinking about what Victorias mental health system should ideally look like, tell us what areas and reform ideas you would like the Royal Commission to prioritise for change? N/A

What can be done now to prepare for changes to Victorias mental health system and support improvements to last?  $\ensuremath{\text{N/A}}$ 

Is there anything else you would like to share with the Royal Commission?  $\ensuremath{\mathsf{N/A}}$