

Submission. Name: Kerryn Lyon

<p><b>Your contribution</b></p> <p><b><i>Should you wish to make a formal submission, please consider the questions below, noting that you do not have to respond to all of the questions, instead you may choose to respond to only some of them.</i></b></p>
<p>1. What are your suggestions to improve the Victorian community's understanding of mental illness and reduce stigma and discrimination?</p>
<p>Ensure that psychiatric and medical staff do not abuse or stigmatize the mentally ill.</p> <p>Do not apply stigmatizing DSM labels. – this can serve to undermine self esteem, confidence and lead already traumatised people to believe they are permanent outsiders without hope.</p> <p>Educate the public as to what is and is not mental illness.</p> <p>Stop homelessness so they do not become more mentally ill and end up in prison.</p>
<p>2. 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?</p>
<p>Reduce costs of getting quality one on one psychological counselling and psychiatric care to a uniform zero.</p> <p>Ensure that all psychiatric professionals are psychologically screened themselves so they do not cause more harm.</p> <p>Allow children to be removed from families that inflict severe psychological abuse.</p>
<p>3. What is already working well and what can be done better to prevent suicide?</p> <p>Qualify psychologists and psychiatrists to a higher standard and create more of them. Be more cautious regarding the use of modern psychotropic medications. Provide hope – not more horror.</p>

<p>4. 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.</p>
<p>Encourage a less abusive, more sympathetic society that values empathy and decency - over money and achievement.</p> <p>Create a less hierarchical system. Consumers are always at the bottom of this system and feel powerless, often suffering consequences when trying to assert themselves while mentally unwell.</p> <p>Create a system that is less de- humanizing – and brings people back to the status of equal, of value and human. Stop telling consumers who they are - or how or what they should be thinking without adequate context and long term one on one positive regard and support.</p> <p>Avoid a rats and stats – where should I fit into this work orientated society - approach to the vulnerable.</p> <p>Foster the positive aspects of difference, <i>+ disability</i></p>
<p>5. What are the drivers behind some communities in Victoria experiencing poorer mental health outcomes and what needs to be done to address this?</p>
<p>Lack of resources. Protracted Poverty and lack of hope just by itself causes mental illness</p>

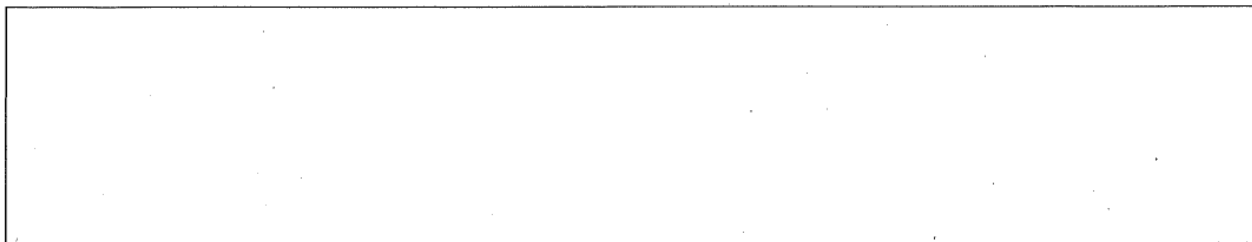
6. What are the needs of family members and carers and what can be done better to support them?

Safe respite care where the family can feel that their loved one is being well cared for.

Re – open safe – progressive – caring - psychiatric housing, units and hospitals to permanently care for the mentally ill if need be. Prisons are not the answer.

If nothing else – just empathy. More one on one help as apposed to dealing with impersonal ineffective - systems.

<p>7. What can be done to attract, retain and better support the mental health workforce, including peer support workers?</p>
<p>Soften bureaucracy and administration – and allow more resources to foster an empathetic work environment that allows them to foster better interpersonal skills and wisdom.</p> <p>More staff – less rigid structure – to allow a sense of genuine community for workers and clients.</p> <p>Lighter work loads so frustrations are not taken out on the mentally ill.</p>
<p>8. 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?</p>
<p>If this is still going on ? - stop enrolling the mentally ill into well-meaning but ultimately exploitative work programs where they are essentially reduced to slave labour. This is demeaning and abusive.</p> <p>Don't try to direct someone into a work or social situation until they have self confidence, feel equal - and know who they are. Otherwise it will be a destructive exercise.</p>
<p>9. Thinking about what Victoria's mental health system should ideally look like, tell us what areas and reform ideas you would like the Royal Commission to prioritise for change?</p>



10. What can be done now to prepare for changes to Victoria's mental health system and support improvements to last?

11. Is there anything else you would like to share with the Royal Commission?

Understand that sadism in the system is real. Understand that while perhaps these people are a minority – sadists - or people with some sadistic tendencies purposely gravitate to areas such as mental health in order to 'enjoy themselves' at the expense of people who cannot defend themselves and who are in essence – pre abused and cannot quickly pick up on being monstered.

In my experience, these people can become senior staff members and thus set the tone of an organisation.

History well and truly tells us that it's a common human trait. More research needs to be given to this area – as many people with a sadistic trait would be considered normal, well-adjusted and not mentally unwell.

And yet this is the cause of so much mental illness.

Privacy acknowledgement	<p>I understand that the Royal Commission works with the assistance of its advisers and service providers. I agree that personal information about me and provided by me will be handled as described on the Privacy Page.</p> <p><input checked="" type="checkbox"/> Yes <input type="checkbox"/> No</p>

From: Kerrylyn Lyon

Royal Commission into Victoria's Mental Health System. Treasury Place. Melbourne. 3300

For the Attention of: [REDACTED] ?

Dear Ms [REDACTED]

I'm submitting two documents to you – one on the advice of [REDACTED] to who I initially sent information to in regard to an abuse that took place in 1983. I hope my information isn't too late to be accepted for the Commission. I understand you're all probably overwhelmed by all the submissions you've had, but hope you still have the energy to read my – first negative experience with a psychiatric professional (attached) as well what I say below which is more of a summary of a life time of diagnostic overshadowing while navigating the medical profession with a chronic illness.

I'll try to keep it short – unfortunately I'm not very talented at condensing complex information in written form - and can see I've repeated myself in places. Apologies right from the start.



27/6/19.

Kerrylyn Lyon: [REDACTED] [REDACTED]



**Medical Diagnostic vOershadowing, Chronic Invalidaton and bullying Document.**

I'm writing this in hope that more recent abuses I've encountered within the medical (and psychiatric system) as a sufferer of Systemic Lupus Erythematosus - along with associated neuropsychiatric problems – (and a kind of PTSD with no 'post' in the term) - can be learnt from by you're commission. (Or perhaps another commission into Doctor abuses ?)

Part of my concern is the medical misuse of what are meant to be good – and well meaning medical 'concepts' – and I do mean concepts – that are concerned with the connection between the mind body dynamic. For me, these have included multiple diagnosis' including ME/ Chronic fatigue - (myalgic encephalomyelitis), Fibromyalgia, and Somatisation and possibly even Functional Neurological Syndrome. (Unfortunately - apart from the medical condition of ME that doesn't get worthy medical research) - these are 'hot' areas of medical research and all are worthy of this. My concern comes from bitter the subjective experience of these labels are being applied to myself (and other Lupus patients) - and how these labels, along with other more general labels such as – 'anxiety' 'neurotic' and 'strange' and 'health fixated' – has interfered with me/(us) obtaining timely medical care - leading to bodily damage, disability and a shortened life span. These terms – when they appear on my medical record – have and still do – lead to dangerous symptoms being ignored, and a kind of medical record – bullying vortex where sometimes quite petty and unfounded opinions about me appear in medical letters that

feeds into yet another psychological assumption – not only in medical letter form but via verbal interaction between Doctors. – One label feeds of another creating a culturally constructed monster called my medical record - this - without any input from me as a patient as to who I actually am and what my psychological problems are.

This has - and is - essentially covert and overt bullying just as you would see in any school yard. These labels are also a great diversion for Doctors who are not confident with dealing with SLE Lupus –which doesn't have clear diagnostic and treatment guidelines. Unfortunately for us without clearer treatment guidelines – as a patient group – we have absolutely no medical legal rights and these labels can be freely used as an excuse just not deal with a medical problem. *(As a patient group we don't have a specialist of our own, so we rely on multiple Doctors working in co – operation with each other which is part of why negative attitudes spiral out of control. I also believe there is an expectation that 'someone' in the group will pick up the slack of another. In my experience this generally doesn't happen. Rheumatologists are seen as the nearest thing we have to a specialist)*

What makes it worse is that labelling all takes place under the guise of decency and kindness – ie – concern about the psychological state of the patient. I'd argue that apart from a few well intentioned Doctors in the system – this is actually hypocritical, discriminatory and an oppressive misuse of power on a systemic level. I say this in such a sweeping way – as I'm privy to research being conducted by Cambridge University regarding the topic's I'm bringing up here. Unfortunately this research is still incomplete – but once published, I'd like to submit it

to the commission as it clearly shows the same pattern of abuse across the board in western countries.

I'd also like to raise a concern regarding the use – or rather misuse of DSM labels. I've accumulated so many different ones of these over a lifetime that recently when I questioned a psychologist about her – diagnosis in the context of so many past labels – without batting an eyelid or further investigation – she told me I had multiple personality disorder. All DSM labels that have been applied to me have been universally distressing and have added to my burden which is one of cumulative trauma. For me these terms have had the effect of making me feel more marginalised from 'normal society' less able to trust myself and less able to participate as an equal human both socially and at work, not to mention being treated as equal as a patient. Being traumatised, isolated and marginalised was the very reason I sought help in the first place.

I've also had breaches of confidentiality within the public funded system where the psychologist needs to write a letter to my GP to continue therapy for (about 6 weeks ?). This clearly impacted my ability to seek healthcare – due to one instance while I was very physically unwell with Lupus – a psychologist – without depth questioning – preferring to assess me via small town gossip and her assumptions garnered from this. She diagnosed me with a health fixation disorder. At the time – I was suffering from autonomic dysfunction of the heart, gut and temperature and could not digest food. I'd also just spent more than a year trying to recover from a renal flare where I was told I was going to lose my kidneys. I was in the process of losing

thirty kilo's and boiling down marrowbone in a desperate attempt to get nutrition as my digestive tract wasn't working and I wasn't absorbing food at all at this time. Thankfully I've retained my kidneys for now and after a long battle for appropriate treatment – I'm now putting some weight back on. (I spoke briefly about this breach of confidentiality at the you're commissions visit to Hamilton, Vic.) After my GP preferred to believe the word of this psychologist over what I was telling him - I had to jump from – what I'll from now on call – the old (GP) practice - to a newly established GP practice – that I'll call – the new (GP) .

At the new practice - eventually – an unsubstantiated psychological label from a Medical specialist interfered with care there. ie: Hysterical woman with stomach problems etc.

I've had SLE lupus for Forty one years and cannot remember one part of bodily damage that I've accumulated over that time that could have been avoided – or at least impact of the flare reduced – if a psychological label had not been applied to me and delayed treatment before physiological investigations took place. I've also consistently had to self - refer to specialists to stay alive.

**I have absolutely no doubt that the current poor prognosis for Lupus patients is in large part due to these dynamics.**

Its impossible to recount all these events that have taken place over a forty one years of this illness - but I might attempt to do a condensed - point by point account of what has happened since 2003 where for the first time in my life I received objective and empathetic medical care

after breaking nearly every bone in my body in a car accident. It's a good indication as to how chronic this problem has been for me as I was actually surprised I didn't have to prove my sanity to obtain medical care in this instance. *SLE/Lupus is an illness that for the most part – happens – un-seen - inside the body.*

In the following accounts I won't mention Doctor names as I'm on a disability support pension and don't want to be sued by them.

Post car accident. I went officially undiagnosed with a mild acquired brain injury: I showed my then Warrnambool GP neuropsychological and speech therapy tests from a TAC claim showing brain damage. He dismissed these as 'legalistic' and tainted – preferring to refer me as an outpatient to Warrnambool Psychiatric services. There I encountered a woman in charge who – being the egalitarian she was - declared she too was one of us - and mentally ill with passive aggression.....and she was - both passively and overtly abusive - especially to more vulnerable clients. I was discharged with a clear bill of psychological health when I was pushed to the brink and asserted myself.

Pre 2003 I was showing signs of a flare – but by 2006 I'd become very unwell with a serious flare. This attacked lining my stomach – causing me to be unable to absorb B12, which lead to peripheral nerve damage and the beginning of autonomic dysfunction. My renal function was also reduced to 50 eGFR and went untreated which was an unacceptable level without treatment. I was unable to get help due in large part to a very senior Associate Professor

Rheumatologist from [REDACTED] (and possibly to a small degree - the aforementioned Warrnambool GP, and Warrnambool emergency department.) Using the term 'anxiety' as an excuse to do nothing. There are letters from this period to support my claim. This Rheumatologist was researching the links between Fibromyalgia and Lupus. His online research seems to view Fibromyalgia is just a cluster of - 'the bad' personality disorders that effect women and he favoured/s the word neurotic. I could not access care to anywhere in Warrnambool. I was going from one GP to another - only to be told that "only neurotic patients do this" I was bed ridden with multiple symptoms and I fully expected to die. Eventually a psychologist suggested I self-refer to a neurologist at [REDACTED]. This Neurologist took one look at me and put me in hospital. I was diagnosed with B12 deficiency which causes de-myelinisation of bodily nerves. I received some treatment in the form of B12 injections but don't think (?) immunosuppression (the medication we take to control the illness and stay alive) was increased to any useful degree. I tried to find another Rheumatologist, but was told "I'd be insane" not to go back to this very senior [REDACTED] Professor. On returning he seemed extremely anxious and had explained that the Lupus had attacked the lining of my stomach - stopping my ability to absorb b12. Stupidly I thought he couldn't surely do the same thing twice. He did.

In 2013 I became unwell again, I'd moved to Hamilton where at that time there was only one medical clinic - 'The old clinic'. Being in an isolated town - they were still behaving like a law unto themselves. Serious symptoms again: bed ridden: serious gastric problems. Three

Doctors attempted to seek help from the senior [REDACTED] rheumatologist. He wrote back to all of them saying 'its most likely anxiety'. Irritable bowel syndrome was assumed – even though I knew this wasn't the case. He was sitting on pathology results showing I was quite seriously flaring( the term used for lupus when our illness is not controlled as it should be ) He'd also misclassified my Lupus as mild. He was aware that I'd had serious renal problems as a teenager which put SLE Lupus patients into the serious category.

The reactions of these GPs after these letters: One was an unhelpful – with no comment – except for some counselling. Another – from a Gastroenterologist at old practice who was actually doing his best to find an answer - (I was hoping this man would save my life) – came back and said "would you like a sedative", and another GP – who after getting off the phone from the Rheumatologist – told me "I wasn't a real patient" and after getting me to stand up she very firmly gouged and circled her fingers into two pressure points that are meant to hurt with fibromyalgia patients. She then walked out of the consultation before I could speak. During this time my mental state was deteriorating – probably from the combined effects of – trauma or neuropsychiatric lupus and declining renal function. I sought help from another GP who initially tried to help – but she eventually made it clear to me - by quite blithely and overtly - not listening to symptoms and then slamming me with an impossible bill (I'm on a disability support pension and she was bulk billing me up until she decided I was unworthy of her care) Finally I realised I was being bullied me out of the place. This was in part – because of the influence of the Rheumatologist, but also in large part due to the fact that I'd made what I

thought would be a relatively harmless internal complaint about what was going on. I can only describe the attitudes of these doctors as viscous. I drove a 200 km round trip to see a GP in Warrnambool (who was very young and in over his head) During this time I also had to learn how to inject myself with B12 as the [REDACTED] wouldn't do this as I didn't have Doctor there. I'd been carelessly misdiagnosed with borderline personality disorder – and I've since learnt that the Doctors at the old practice considered 'me' a psychopath due to this diagnosis, perhaps the diagnosis of Fibromyalgia as interpreted by the Rheumatologist – (along with the quite mild internal complaint). These things apparently rendered me - unworthy of their time – perhaps in their eyes – unworthy of life ?

In reality I doubt whether these Doctors gave any of this a second thought, but I was too unwell to move away and seek care elsewhere. The [REDACTED] Hospital emergency department also turfed me out about four times— because I was 'anxious'.

Eventually, the [REDACTED] Rheumatologist tested my catecholamines..... twice – they both came back negative. Back then catecholamines were thought to be a marker for fibromyalgia – but nonetheless – during one of the [REDACTED] emergency department visits I did manage to ascertain that I had unacceptable levels of protein in my urine that didn't raise any eyebrows their. (sign of renal failure again) – So I told the Rheumatologist. Eventually he tested my renal function. Again – I'd been bed bound for nearly two years strait. The kidneys were almost destroyed at this stage. This was 2015. Just previous to this he'd taken me off all immune – suppression (medication for Lupus) altogether and had sent me off for trans cranial



stimulation. I'd requested the TNS due to a chronic balance disorder – but I later found out he was researching this as a potential treatment for fibromyalgia. The TNS had to be halted due to an adverse migrainous- perceptual effect that lasted a month.

When this Rheumatologist rang and told me I had a renal problem. I asked whether it was serious – he said – “no, if it was I'd have you down here today, no in thee of four days will be fine”. I asked whether it was lupus, he said no. (which was disconcerting as the only other option in my own mind – for a lupus patient my age is Lymphoma) I waited to go to Melbourne but I ended up having to ring and re – ring until his receptionist said – “don't worry, - I'll make him do it” It took about two weeks. I was close to renal failure.

The first thing the Head of department nephrologist at [REDACTED] said to me when presenting to him – was “What – did he think it was anxiety”.....followed by – yes, he's a very elusive man. Then he explained that he thought I'd probably lose my kidneys.

For a year or so I received respectful and good care and managed to retain my kidneys. But only just. I believe it's still expected that I'll lose them over time

All was somewhat fine until recently my digestive system essentially decided not to work and all of a sudden I was lumped with ‘the health fixation disorder’ from the previously mentioned local Psychologist. I had to jump practices. Thankfully a newly arrived GP practice now had set up shop.

Then when another specialist declared my gut problems were psychological as he couldn't figure out what was going on – and it all started happening all over again.

I did have a gastroscopy which showed a stomach full of undigested food. The surgeon who performed the procedure diagnosed gastroparesis. This surgeon was aligned to the new practice. They had to import their own hospital staff due to competition between practices.

Nonetheless I was asked after the procedure – whether I'd followed the instructions for fasting the day before. I said yes – of course – but now looking back - see I might not have been believed.

During this period I was also used as a pawn by the local GPs as the two medical practices were competing for patients. The new practice had ceased trying to help – with my gut problem due to more discrimination ? (or perhaps possibly because they'd safely established their practice and understood just as well as the old practice had done - that didn't have to do a thing if they didn't want to?) This seems to be the lot of this country town. So I decided to go back to the old practice as the GP I'd left behind is medically competent when labels aren't effecting his behaviour. I take Xanax and had transferred the authority to a GP at the new practice. My current GP was slow to act in obtaining the authority himself and told me to go back to the new practice for one more script. I'd attempted to get a copy of my medical records from the new practice, but they purposely printed it out blurry. It was obvious the two practices were not sharing medical information or hospital resources. This did not help with diagnosis. On returning to the new Practice for the Xanax the GP was about to write the script - until he had a

thought bubble – and told me he wasn't going to do it. He then beckoned two other GPs into the room to – and standing over me essentially tried to blackmail me into staying at the practice while hinting at personal grudges with my GP at the old practice. But they didn't put any of this to me in clear or overt terms.....so - very confused – I went back to my now current GP and after yelling at these GPs over the phone that they were unethical - he told me that they were doing this just to try and keep me as a patient. At this point I had lost close to thirty kilo's in weight. I can only thank god that I was obese to begin with. I was again becoming very unwell again and was spending most of my time in bed, unable to eat or absorb food and being well aware I had autonomic nervous system problems - I couldn't withdraw from Xanax. One day - half dead in bed the new Practice had rung me and asked "What do I want ?" I believe at that point I'd threatened them with reporting them to the health commission. I said "I just want my prescription".....they didn't quite believe this and continued to ask – "no....what do you want". In the end - they gave me half a month's worth of script to shut me up - but I still had to self source and self refer – via my GP - to a willing psychiatrist (rare at that point in history) who would authorise a new authority. I also received a trail of nasty defensive emails from the new Practices head office.

In 2017 -2018 the gut problems were - formally diagnosed and treated. I'd lost thirty kilo's in weight during the process. I was diagnosed with a slow gut and associated autonomic problems I was also low on digestive enzyme production. Before the 2015 renal failure – I'd been taking a small amount of Creon (digestive enzyme in a pill) which had bought back a lot of energy and

had got me out of bed – but the Gastroenterologist that prescribed this described this as a sugar pill effect. After the renal flare I was told by nephrologists that my gut problems were due to the kidney flare. The digestive enzyme insufficiency went undiagnosed. On this advice I stopped taking the Creon.

As things are now - I might be suffering a decline in memory ? I was sent back to the tender mercies of the neurological department of [REDACTED] Hospital. I sought out help from two social workers to help me face this medical department again. On re-entering this department - the autonomic heart dysfunction due to lupus (or B12 deficiency causing damage to the dorsal root ganglia nerves- was re – diagnosed as POT's (Positional Orthostatic Tachycardia) and attributed to anxiety and psychological problems. After new state of the art MRI and PET and SPECT scans – showing acquired brain damage from the 2003 car accident – I was diagnosed with 'Somatisation' - (or possibly Functional Neurological Syndrome – like so many of my Lupus contemporaries around the world ) I had a letter war with the genuine and very well meaning man who diagnosed me with this. He counterbalanced his diagnosis with a plea to all my other Doctors to stop the chronic bullying. I desperately tried to spell out to him how dangerous it is to have this diagnosis my medical record and could he please keep – what is essentially Freuds conversion disorder – (much the same as how my ex Rheumatologist defined Fibromyalgia) off my medical record as I have an illness that can randomly attack any part of my body. Unfortunately He seemed morally hell bent on teaching all other Doctors about it.....for the greater psychological good, In November 2018 the iron deficiency followed. I

literally couldn't breathe easily due to reduced red blood cell size. Initially couldn't get help with a fill in Doctor at the old practice - who on the day tested my breathing capacity and after consulting my regular GP about the issue - was told there was nothing more he could do. Upset immediately after this I drove to [REDACTED] Hospital emergency department - pale with blue extremities - but again - after being tested for a heart attack, and some blood tests taken - I was told it was anxiety. I had booked an appointment with a new GP in Warrnambool the next day. When I presented to her she was quite impatient and asked "I have other patients with chronic illness such as diabetes, why can't you cope with yours?" She continued to be very disrespectful until I let her suggest a list of psychologists I could see. The look on her face was - 'thank god the idiot had finally listened'. Following this my regular GP sent me for more formal lung tests, but he was looking in the wrong place and there was no follow up. I tried to get help from my Rheumatologist twice who's based at [REDACTED] Hospital but she didn't respond at all. I went down to see a fill in Rheumatologist - but I after looking for - body surface symptoms like arthritis and rash (signs of Lupus) - did nothing. Finally the iron deficiency was diagnosed via me googling and dropping every hint to my Nephrologist. All this lasted about three to four months. I can only assume they all thought it was a panic attack. I've never had a panic attack in my life. I'm still suffering from chronic anaemia - and investigations as to why this has happened has been slow. I've repeatedly told Doctors that I eat plenty of red meat. I'm only now (July 2019) starting to get appropriate investigations. Up until now - much needed iron infusions have been sporadic and I've had to become anaemic again to

receive a recent infusion (24<sup>th</sup> of June, 2019) I believe this has more recently been part of a genuine diagnostic process ? – but before this I believe chronic invalidation of symptoms had somehow continued.

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I was recently asked by this RHM nephrologist whether I'd like to participate in a study on autonomic dysfunction. When my GP mentioned this – I told him if the study had anything to do with somatisation – I would not participate. Nothing more was said.

Its my opinion being research fodder all seems to be the trade - off for being relatively poor, neuro - psychologically vulnerable – and a public patient. Even with these trade-offs it's become obvious from some awful interactions with specialists recently - that being a public patient means me and pretty much everybody else without private health insurance cannot access specialist medical care when things become semi – urgent. This is a relatively new and insidious development.

It would seem in forty-one years I've come full circle. The discriminatory '*attitude*' of my medical record does not self - correct with correct diagnosis' after long and body damaging delays in treatment. Not so long ago I attended the local Emergency Department – only – again to be told to go home. When I refused – they admitted me – and again – half dead – had to prove that I wasn't anxious.

I still suffer chronic invalidation from Doctors who still do not understand why I am sitting in front of them.

It's possible I may have the early signs of neurological executive function decline – from the car accident injury – combined with many years of untreated SLE neuropsychiatric flares. The possible diagnosis Functional neurological syndrome – may possibly be my the last insult. This one is just plainly obscene and it has crossed my jaded mind that I was being 'triaged' for a longitudinal study - despite the profound decency and concern of the man who labelled me.

One neuropsychological assessment (post autoimmune hepatitis 1990's ) – conducted under the care of the earlier mentioned [REDACTED] Rheumatologist - made its way into a longitudinal research project on neuropsychiatric lupus – without my consent. At that time I didn't know I was being researched. I was also not given any meaningful feedback of the results. (except being told I was fragile and expect too much of myself) The study showed I'd suffered the effects of Neuropsychiatric lupus. I was struggling at University at the time.

Studies vary as to the prevalence of Neuro -psyciatric lupus but its thought up to 80% of patients are effected by it to some degree. This can range from chronic headaches – all the way up to massive brain damage. I believe this is a large part of the reason why we – as a patient group suffer from disproportionately to bullying, invalidation and diagnostic overshadowing. 98% of us are also female.

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This has been a life time of horror for me that will haunt me to my grave. My quality of life and life span itself has been reduced by this behaviour.

The effects of the illness itself is unpredictable and devastating. My level of Lupus means that it's a terminal illness – just like terminal cancer. I was recently told that the average life span for someone like me is 53 years of age. I'm 51.

But to have spent most of this life – begging for medical help from petty bullies has caused a trauma that is just so much more profound that recently I've eased up on seeking medical care – and have considered not even seeking still much needed medical at all - due to – even good Doctors being too great a trauma trigger. I understand this dynamic and am seeking trauma counselling for it so I can continue to fight this disgusting fight. I am just so tired of being the psychological scape - goat of Doctors who feel insecure with dealing with this disease - but because they cannot acknowledge this about themselves due to their own psychopathology - prefer to abuse me.

The above mentioned neuropsychiatrist told me that childhood invalidation leads to adult invalidation. He is absolutely correct about this – but I believe had I been spared a lifetime of medical abuse, I'd be a relatively well adjusted human being.

Also - for sufferers of Lupus – or sufferers of other under researched medical conditions - especially where there's thought there may be a mind body connection – there has been – and still is a real danger of bodily damage and death due to these insidious trends that just never



stops....just never lets up. This is simply Freuds conversion disorder –hidden and re –  
 combobulated into the complexity of modern medicine. In arguing with my well meaning –  
 young - neuropsychiatrist I pointed out to him that in the twentieth century people with mental  
 illness were left – for years - with untreated broken arms and legs in psychiatric institutions due  
 to Freuds theory. Unfortunately you don't have to think too hard how these poor people met  
 with broken limbs in the first place. I hope you're commission is not finding similar abuses  
 now.

I have never presented to a Doctor with a false symptom. Not once in 41 years yet I believe I'm  
 still viewed as a hysterical time waster.

Interesting medical concepts - academic wankery and the shallow– unqualified psychological  
 ponderings of Doctors without psychological degrees - who hold positions of profound  
 responsibility and power have my life one of constant terror. In my case – Doctors seem to  
 behave no better than the sadistic petty school children that I dealt with as a teenager.

I was about to finish this document off by saying Doctors have forgotten what they're job  
 description actually is – but with forty one years of inexplicable chronic experience of this - I  
 wonder if they ever knew.

*I'd be more than happy to hand over my medical records – as it now stands right now – to prove  
 my point. I've gutted my medical records on several occasions over a life time and know what I  
 say here to be accurate.*

Sincerely

Kerryn Lyon

[REDACTED]

[REDACTED]

For: Royal Commission into Victoria's Mental Health System

From - Kerrylyn Lyon:

Dear Health Commission.

My Mental Health problem is one of cumulative trauma. A kind of Post Traumatic Stress Disorder with – no post in it. This is due to having to spend – what is now 41 years of my life – fighting for my life – with an illness called Systemic Lupus Erythematosus (SLE Lupus). For me its an aggressive level illness that can attack any part of my body.

The core of my - complaint/s - is due to the chronic nature of having to fight – to get medical care for an illness - that I strongly believe – Doctors would prefer not to deal with. Some years ago one GP was honest enough to tell me “we don't like dealing with it due to the nebulous nature of the illness”

There's also a strong neuropsychiatric element to this illness – that now - looking back – I've probably been mildly effected by. It's a very common feature of the illness.

This may have left me with some mild brain damage. Despite this I managed to get through five years of University – A Bachelor of Fine Arts, - A Graduate diploma in Secondary Education, and one year of Anthropology (with a little bit of medical anthropology thrown in)

Over the past 41 years – pretty consistently – when trying to get care for physical manifestations of the illness – Doctors have near constantly fobbed me off with various psychological labels, suggestions that I need an anti – depressant, learn to meditate, or see a psychiatrist. This problem has been terrifyingly chronic and persists to this day. The most

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recent example of this was me suffering from an Iron deficiency anaemia – to the point where my red blood cells had reduced in size. This caused difficulty with breathing (along with many other symptoms) From November 2018– to February – 2019 I was unable to get help with this due to an assumption that it was a panic attack. I literally had to google the diagnosis myself. This dynamic has been my life. And this is in essence - why I'm writing to your commission.

In 2003 – I was a passenger in a car accident (where I lost my partner ). On the 8<sup>th</sup> March 2018 due to concerns about memory and my neuropsychiatric state – I had some latest technology Neurological scans that show I have mild brain damage to the pre frontal and mid cingulate region – consistent with post traumatic brain damage from this car accident. These injuries were underestimated at the time of the accident – so I've essentially been wandering around with undiagnosed mild brain damage for sixteen years. I accessed copies of these MRI, PET/CT and SPECT scans myself after a diagnosis of 'somatisation' (or functional neurological syndrome ?) followed the scans. I utterly reject this as inaccurate and – and an extremely dangerous thing to have on my medical record as my level of SLE lupus is serious and classified as 'undefined' meaning it has and can attack any part of my body. I believe having this level of Lupus and a clearly sighted acquired brain injury would be a diagnosis of exclusion for a diagnosis somatisation.

This happened at [REDACTED] Hospital. 2018

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I'd describe my neuropsychological state since 2003 as a kind of – mild psychological locked in syndrome – where my intellect is in tact – but executive functions have been mildly compromised. ( I have a copy of a recent neuropsychiatric assessment – again from [REDACTED] [REDACTED] Hospital )

Since the car accident – It's been a little bit like watching a nightmare of all forms of diagnostic overshadowing unfold in front of me almost non stop. Recently I've discovered – when a Doctors appointment go's very badly – with various forms of being fobbed off- if I can write to them - via email – demonstrating to them that I'm actually competent and 'in here' – they become a little bit terrified – realizing – that amid the muddle of bullying and discrimination – I'd recognised what had happened – and had caught them out. Its not a great way to get a Doctors to do their job, but to some extent it's how I'm currently been obtaining medical care.

I should stress that I never fail to clearly express – what my physical symptoms are. When seeing specialists – I write symptoms down for Doctors to read if words fail me. (this in of itself – had been seen as some kind psychologically aberrant behaviour).

I believe given slow verbal scaffolding – I'd be able to be a co – herent witness.

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Ultimately though my complaint is in regard to my first experience of my medical care being compromised by a Doctor who took advantage of me when I was in an extremely vulnerable state for psychological research purposes. The name of this individual is not known to me – but

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recently I rang [REDACTED] Hospital Medical records – and learnt that my records from this era is still in tact. I'll be obtaining access to these records.

- The following complaint is against – Either a psychiatrist or psychologist at [REDACTED] [REDACTED] Hospital who behaved unethically in 1983. I'm sending way too much information – as this is an edited version of text designed for another purpose. It does describe events from ages - 9 to 15 and provides context for the event. I'm 51 years of age now.

I Started to develop on and off symptoms of Lupus with early menstruation – age nine. Bouts of nausea for a week - near menstruation. Increasing fatigue. This happened in what I now know to be periods of Lupus activity – or what they call 'flares' where I'd have distinct periods of wellness and unwellness. My mother took me to GPs during the period – it became a bit of a running joke – “oh does she need some flat lemonade again” so re – hydration could take place.

*Both my parents were generally very good at looking after my physical needs – re: good clothes, grooming, food, etc – but both were at the scary end of the emotionally abusive scale. From secondary school I was also bullied at school. This didn't set me up to be a very assertive teenager or younger adult. This – along with future (neuropsychiatric problems from SLE Lupus – (that I'm only just properly learning about now) lead to – a form of cumulative trauma – anxiety based (mental illness).*

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From about the age of twelve to fourteen the illness became worse. I began to develop pain particularly in one ankle – but also in other joints. My muscles were also weakening and I was so tired I could barely stand. My mother observed that “I was hobbling about” while I tried to do chores on the small farm we lived on. I was also still vomiting every month for about a week - and still thankfully – going to school.

My first visit to a Doctor due to increased symptoms was somewhere after 12 years of age. I was placed on the examination table – the doctor placed his hands under my knee and foot – saw they could bend – and told my mother it was growing pains.

The second visit involved this Doctor sitting – quite sternly in front of me – and saying “You don't like school much do you”

There was a third visit where I attended a gynaecologist appointment to see if he could find a link between the vomiting – and menstruation but he had nothing to add – and for the first time in my life I wondered why a Doctor wouldn't refer me to someone who might have an answer ? *Still a problem today.*

By the time I was 14 I had on and off again redness and swelling of my ankle joints – vomiting and recall an incident with my mother where she wanted me to chop some wood. I was too weak to lift my arms – let alone an axe. I did the best I could and I came back a little low on product. She made me go back and get more despite me begging not too and almost collapsing from fatigue. after all - the doctors had told her this was all put on - it was all in my mind – so there was no relief from this torture.

At this stage I understood myself that I was extremely unwell and unless I got medical help I'd die. I remember thinking this while sitting in the car after my mother had taken me to one last GP. She'd stayed behind to speak to him afterwards. When she came back - she thumped the car door closed and said nothing. There was no answer.

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I was urinating a lot at night – and had to use multiple ice cream containers a potties. I showed my mother a sample of a nights work which was filled with a white filmy substance – it looked like it chock full on spiders webs. (I now know this to be severe proteinuria – due to the lupus attacking the kidneys) An absolute non reaction from her – perhaps except for the above stated last appointment ? The order of events were becoming muddled at this stage. I was becoming extremely unwell.

Then finally one day at school I sat down on the grass with a friend but when it was time to get up and go back to class I just couldn't get up from the pain in my ankle. I don't actually remember what happened next – but logic tells me that several teachers literally had to pick me up and carry me to a car and take me to the same GP office. My memory kicks in when they placed me on the floor of the waiting room and summoned my GP. He came out – but refused to bend down and feel the heat coming off my ankle. (it wasn't swollen or red) The teachers – who'd been watching my health decline for some time simultaneously started to yell at him to do it. Eventually he begrudgingly bent down and felt the heat coming off the inflammation. After this – no memory. This GP completely disappeared and was never seen by me again. He was replaced by a very junior and somewhat frightened looking GP – probably just out of medical school.

I don't know how long it took but a general specialist was called in. Dr [REDACTED] I remember him as the first gentle warm Doctor that I'd ever come across – and the first Doctor without a smug opinion about my motives and mental state. He did a complete head to toe examination and apart from heat coming off my joints he also detected heat also coming off my Kidneys. I don't know whether he'd figured it out on that first consultation or if I saw him twice ? but he said he was going to admit me to Hamilton base hospital. – I remember asking -do I need an operation ? – “No don't worry - what you have only requires medication”. I was 14 – nearly 15 years of age. I was never accompanied to a medical appointment with a adult again.



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*I've since learnt that my mother had rung people upset as the Doctors had told her off. I have no idea what they said to her. I don't recall what my father was thinking? – apart from an obsessive desire to discourage and undermine me in every possible way – at every waking moment – during this period.*

I was referred to the [REDACTED] Hospital Renal department as an inpatient - where I was placed under the care of Professor [REDACTED] (I've since been told that she only took on quite serious cases) My parents were there – but I don't remember seeing them much. All I know is that my parents were very intimidated by her and “her fancy consulting suite”.

I quite liked her. One – she was the first female Doctor I'd ever set eyes on and she was VERY confident and declared – “nobody dies of renal failure on my unit” which was reassuring – the only trouble with that statement was – I didn't know I was close to losing my kidneys. I hadn't been informed.

I was sent off for a Renal biopsy. In those day's they didn't have ultrasound to help guide the procedure - so it was literally a wild – multiple stab at it. Laying on my stomach I was surrounded by about 15 surgical staff in a operating theatre – and was told to breathe in and hold my breath until they said I could breathe again. They had about six to seven go's at it – and at one point they had forgotten to tell me I could breathe again – and when they discovered this they found it quite funny. I tried my best to laugh along with them.

I was sent home after this and at my next appointment with Dr [REDACTED] he told me I'd be taking prednisolone to treat my lupus. 60mg as well as high dose cyclophosphamide. I must have asked about side effects and he said – you might gain some weight, but – don't worry – prednisolone has a tendency to make people happy.

So I went home waiting for the happiness to kick in. I didn't go back to school. (It might have been close enough to summer holiday's which was almost two months back then.) The

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only problem was that the happiness didn't happen. Any dose of prednisolone over 40mg makes a normal adult mentally ill. Prednisolone is quite literally anxiety in pill form. It took three or four weeks but I remember starting to feel the bend in my mind. I'd quickly and utterly forgotten about my teenage concern about weight – this was the very last thing on my mind. I was more confused and concerned about my mind.

At first it was a flat line anxiety that I just had absolutely no reference for - and I was used to anxiety. If you can imagine you're worst 'normal' anxiety reaction and multiply it by about 70 you might get somewhere close. But there was a warp to it as well. Some awful extreme emotions that are just not expressible in the English language. Something that doesn't exist in the normal emotional range at all. It was utterly terrifying and I had no way to relay these emotions to anybody– and nobody to relay them to anyway. So I just endured the slow growing ache like distortion that was my declining mind. My body began to bloat up except for matchstick legs and arms. An obese torso and extremely puffed up un – natural looking round face appeared along with an unstoppable desire to eat. I ate things that I wouldn't even look at today. My fathers recollection of this – “You would have stolen anything off my plate”

Finally I reached a point where I could no longer tolerate interacting with anybody. The world seemed like a terrifying place and I just couldn't cope with both it or the chemical change that was happening in brain and body. We used to go on caravan trips to the coast during the summer – and that year – given nobody really understood what was wrong – It was thought it would be a good idea to invite a first cousin who I was close to to come along. She was lovely but I couldn't cope with her either. My mind was completely lost. She ended up in tears because I couldn't handle being anywhere near her – or anybody. I was near beyond speaking. I remember feeling very guilty for making my cousin upset. Enormous – amplified guilt. I'd also developed OCD type symptoms of the type that if I didn't do things like - touch something twenty times – or even worse - do something humiliating – like lick a

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dirty puddle – then something awful would happen to mum and dad or a natural disaster like the sun imploding would leave humanity to starve to death. (although I never followed through on the worst humiliating actions) I remember looking at every sunset – for a set amount of time every evening as it was going down – in a superstitious OCD way to ensure its longevity. I'd also started to become hyper religious and prayed for a certain amount of time that the sun wouldn't explode like a dying star does.

Eventually – after several months ?

I ended up at Dr [REDACTED] office again – probably just a periodical review ? Again – one examination and I was booked to go via air ambulance to [REDACTED] Hospital three days later. He said he wanted me to go to see if the SLE was effecting my brain. (again no parent present)

In the meantime – the wind had kicked up in furnace like conditions. “Good weather for a bushfire” my mother told me – possibly on the way home from this appointment. The whole world was parched.

She was not wrong. The Ash Wednesday (fires) happened the next day. I woke up in a house surrounded by smoke. You literally couldn't see one metre through. Nobody really knew what was happening or where the fire was. The power was out so there was no radio communication . My father and I ended up driving through the eerie smoke fog to see why. We suddenly drove into a small sphere of human activity where a police car had just quickly driven up – only to quickly back off due to being on top of a fallen power line. That's pretty much all I remember of that day.

The next day – or day after - the smoke was only just lifting when I was due to fly to [REDACTED] Hospital. But there was one other patient. Someone on an ambulance trolley. It was a man, or at least at that age I thought he was a man – he was actually not much older than me and he'd been a volunteer firefighter and his whole body was badly burnt. He was put on

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the plane first and somehow (?) my mother had to ? - or offered - to quickly take over his hand pumped air ventilator and just while I was stepping in and was seeing all this I was asked whether I'd like to sit with the pilot. Not really a question.

I remember the flight and looking down at the smoke creeping up from hills of Mt Macedon on the outskirts of Melbourne.

.....

Once at [REDACTED] hospital I don't recall really seeing my mother again. She was staying at her first cousins place a few blocks away.

I remember sitting in there actually hoping that there was something physically wrong with my brain – then at least there would be an answer – and even though I knew there was not much they could do about brain damage – for some reason I thought the diagnosis might somehow stop my suffering. It would be an answer at least.

With the Obsessive Compulsive Disorder symptoms I was still hyper - religious in a very warped Christian way - and I remember praying for the young man every night until one night I forgot to. I was told the next day that he'd died. So I literally believed it was my fault and felt extreme distress and guilt. Unfortunately for me at this time I was there to see a neuropsychiatrist – or psychologist (?) who technically should have performed some standard formal neuropsychology tests. I'd been doodling cartoons and I think he asked whether he could take them. They became part of my medical record. Cartoons of rats bullying rats.

After some very gentle but brief questioning from this guy – mostly about what I remembered in the news over certain years he asked would I be willing to come to another section of the Hospital and there I'd be asked some questions in a room with a couple more people there. I thought what harm would that be – and said yes.

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In the interim about two – maybe three young female psychology staff – one at a time - on their own – very quickly with a distressed look on their face visited me – and just told me “you don’t have to do this”. But they didn’t add any more information to this and being young and not exactly in a fit physical or psychological state I didn’t think to ask them why they were telling me this. Thinking I was going to have a gentle chat with a few people - I told them “it would be ok ?”

I was taken in my hospital nightgown to the other side of the Hospital and was lead into a near pitch black dark room. I was told to sit down. In front of me was a video camera and equipment with about two other men in the room. A blinding bright light was shone in my face so I really couldn’t see anything else around me except blaring yellow white light. Standing in a corner of the room the psychiatrist just started to ask questions but this time they were more personal. In fact I wouldn’t call it – asking questions – it was more of an interrogation. It was just like what I’d seen in old gangster films where the criminal is being violently – emotionally beaten about with a blinding light shone in the face. At first he started by asking the same benign questions he did on the ward – what news items over the years I’d remembered and forgotten. But then the emotional intensity of his questions escalated. He was trying to prove that I’d repressed years of memories. He was also attempting to prove the fact that me being upset about the fire victim’s death was in fact a form of Freudian displacement from my real problems which was being bullied at school. (the doodles led him to this conclusion). As the ‘interview’ went on he was literally trying to make my mind snap under the pressure of his questions just to prove his point. I remember looking to the side of the room essentially for help and saw there were rows of people watching though glass and I could see one woman was crying. Eventually after about – what seemed like half an hour – perhaps more – (?) I started to buckle and cry under the strain and as I did so - he literally snapped my already broken mind and left me in such distress that to this day I’m unable to trust psychologists or psychiatrists. Somehow amid all this one of my final answers was just

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what he was looking for. When he'd gotten what he'd wanted out of me and proven his point a smile came over his face that was in contrast to his previous facial expressions and psychologically aggressive demeanour. After this the lights came on and I recall just how sickeningly pleased he was with himself. I almost expected him to take a bow. He could now reveal to his audience that my real problem was being bullied at school. As I sat there - he then made a speech to his audience regarding Freudian displacement - where the mind creates diversions (ie - me distressed over the death of the CFA volunteer) to create a distraction from my real underlying trauma - which was bullying at school.

I didn't receive the proper neuropsychiatric assessment that I was sent there to get.

There may be a - video recording in existence of what happened.

This man was in his late twenties - possibly early thirties - and is possibly still alive and practicing ?

Dr [REDACTED] is still alive. He works for a medical insurance agency - and was once a senior figure in the AMA (?) ( observed online ) He may remember the identity of this individual.

Dr [REDACTED] saved my life and did absolutely everything correctly.

.....

Later on I was referred to a travelling psychiatrist - who while helpful on the odd tips for OCD, was also a condescending sadist who - was also into humiliation. After he had deduced the same Freudian theory for himself which apparently was my only point of interest - he repeatedly told me I was boring. I was a bit slow on taking the hint and without an adult present - I kept coming back as he was the only option I'd been given in. He continued to escalate his sadism and make things worse. A farmer who lived near by killed himself with a diagnosis of schizophrenia after receiving 'care' from this man. At the time I wondered



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whether he did this because of this bastard's nature. ( His name was Dr [REDACTED] He would most likely be dead by now )

From what I gathered at the Royal Commission visit in Hamilton – the quality of psychiatrist/s (?) at Hamilton may only be marginally better ?

Not so long ago I recounted the [REDACTED] Hospital incident to a fairly good Warrnambool psychologist. She said absolutely nothing and changed the subject. **My concern is – does this kind of thing still go on ?**

.....

During this same hospital stay because my body shape that had ballooned I'd been repeatedly asked was asked whether I was pregnant by various staff members. I told them no I wasn't. (They had to know as a pregnancy would have killed me – but I wasn't aware of this fact at the time – they just told me pregnancy might make me sicker) They didn't seem satisfied with my answers and eventually they sent in the big gun - Professor [REDACTED] herself – who literally never stopped walking – quite literally never seemed to cease activity of any kind – who quietly sat down and asked me – “whether perhaps I might have gone to a party – perhaps with some boys – perhaps had gotten drunk and couldn't quite remember” etc. I felt like I was being treated like a country moron who didn't even have the facility to know the basic facts of life. The ward was literally filled with large and small collections of gruesome looking urine samples so I just replied “You can test my urine if you like”. By the look on her face I think she was shocked that I'd actually become a sentient being. (still a common reaction with Doctors up to this day) She back pedalled a bit and asked whether I was overweight before the medications. I told her only a little bit. “Oh well – that explains why you're overweight now” as she walked off. A bad memory – but she did the right thing. I was actually grossly overweight from the effects of the Prednisolone. I was 16 stone (modest estimation) , all fat

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and fluids going to my torso and face. I had abnormal skinny arms and legs for contrast. It was Cushing syndrome. (hypercortisolism)

.....

Then I came home and saw Dr [REDACTED] who was as always - was sensitive and kind. But by this appointment – I was probably near mute from trauma. He pretended he couldn't work out a simple prescription under five digits and he asked for my help. When I found I couldn't he uncharacteristically lost his temper. At the time I thought it was because I couldn't help him and thought I'd done something wrong. Once he'd regained his composure a little he apologised for sending me to an adult Hospital instead of the Royal Children's, but he did it because [REDACTED] Hospital had the best renal unit. It was the only apology I've ever received from a Doctor (and none of this was his fault). At the time I had no idea what the real issue was. With SLE – if you have a severe (renal) flare - you're more vulnerable to neuropsychiatric lupus. I may have been slightly brain damaged ? I could do maths in primary school, but not secondary. It's was either – neuropsychiatric lupus and the effects of steroids – or both, not to mention traumatic factors.

At school I had two friends before diagnosis. On a school trip to Melbourne – one had literally told me "I cant just leave you sick in bed only to go off and enjoy myself" – so I followed her out onto hard concrete for long walks as my mind was still able to enjoy things back then - even though I was sick. This was one of the periods where my ankles did swell and go red on and off. I remember the relief of finally sitting on a tram seat when one indignant Melbourne adult gave me good sound telling off for sitting down when older passengers where standing. My standing classmates looked at me with real pity as I had to try and stand up again.

Now – after these experiences of the adult world - coming back to school I felt innately different. I saw the shock of their reaction to my physical appearance – but it concerned me



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way less than it should have. My mind was too far gone – I didn't care about this much at all. The schoolwork in class was literally too difficult to follow and - now too irrelevant to try and waste what little amount of emotional and physical energy I had left. It was obvious my fellow students had been told not to bully me – one brave boy tried – but was told to shut up by his friend. It was a major change. I was left at peace at school – but not at home. The contrast was too horrific for me to cope with at this stage and I remember retreating into an old hollow shrub that doubled as a cubby house for me and my siblings when we were younger. I used to get away from my parents by climbing the trees – or sitting on the roof - but I no longer had the health to escape very far. I remember while sitting there, by now rocking back and forwards from trauma - understanding clearly that my father – who was relentlessly applying psychological torture to me at this stage - didn't have as much empathy or insight as a 15 year old teenage boy. I knew clearly for the first time he was trying to make himself big by making me small. I was still obese from the prednisolone – and had lost a lot of hair from the Lupus & cyclophosphamide. He took mug shots of my body – side and front. I had no choice. When my mother caught me rocking back and forwards from trauma – her comment was mockingly “ why are you doing that – only old people do that” - and when she took me down the street – every shop we went into – she apologised for my appearance. When I walked alone on those streets I was taunted by packs of teenage boys. Technically I was still in danger of dying but my understanding of this was only instinctive. I had no words for it back then. I don't really do now.

People define these states as mental illness. For me I've always bristled at the term even though since this period I've never been able to feel like an included – normal human being again. I'd define my state of mind as a normal human reaction to a merciless world where vulnerable children are fodder for predatory individuals to be used for their own agenda and amusement no matter how horrific the context.

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After all these events had settled somewhat - I recall a GP saying to me after diagnosis that Lupus is "such a rare disease" and was handed some pamphlets about it. I had a bit of a read on the way home. I thought I was bad at maths (and had stopped trying to keep up with it at school ) but it said it effected one in several hundred people ? (300?) ? I thought to myself – that's not that rare ? Then later I read one of the pamphlets in more detail. It said my average life expectancy would be five years. I remember reading – and then re – reading but the writing didn't change no matter how hard I tried to re -interpret this statistic. I had absolutely no will to ask an adult – and simply had no adult to ask. I'd totally lost the ability to trust anybody. So I just put the pamphlet down and tried to carry on as if nothing had happened.

I left home for art school in Melbourne when I was 17 to complete a fine art Degree. I was in a whole lot of hurry to paint pictures, but not in much of a hurry to speak to my fellow human beings. I'd totally lost faith in humanity. Right up until my late twenties I was expecting to die. I took the bare essentials of low dose prednisolone but I think it might be possible (?) that I didn't even attend a specialist clinic again until I was twenty six years of age and had moved from Melbourne to live in Cairns. Up until that age - I don't remember being told I was meant to be under the care of a specialist. I Just attended the odd different GP visits for prescriptions. No questions, no advice given.

Nothing at all.

**This is a quote from a recent Psychiatrist letter, dated – 8<sup>th</sup> April, 2019**

**.....On MSE neatly, casually dressed and groomed, normal speech processes, affect appropriately reactive, no thought disorder; no delusions/hallucinations: not suicidal, insight and judgement in tact.**

For: Royal Commission into Victoria's Mental Health System

*Sincerely,*

Kerryn Lyon

[REDACTED]

[REDACTED]

*Kerryn L. 27/6/19.*