



## WITNESS STATEMENT OF EMILY JOHN

I, Emily John<sup>1</sup> say as follows:

- 1 I am 18 years old and have been a carer for my mother my whole life, but particularly since my mum had her first mental breakdown in 2014. I was 13 years old at the time. I have also had experiences with the mental health system myself.

### **My experience as a carer**

#### ***Mum's psychiatric admissions***

- 2 My mum's first admission to the psychiatric ward was through the Crisis Assessment and Treatment (**CAT**) team. She had been out of a physical rehabilitation program for pneumonia for only about 24 hours before she was admitted. I remember getting picked up from school by my Pop. My mum was in the car. Pop told me mum's suitcase was in the car and we were going to a psychiatric ward.
- 3 I remember the ward seeming old and out-dated, so it was really scary. The CAT team met us there and I remember bawling my eyes out in front of one of the team members. They set up a meeting for me with someone from the Families where a Parent has a Mental Illness (**FaPMI**) program.
- 4 FaPMI were really good and they helped refer me to the young carers program within Carers Victoria for additional support. When I was in the young carers program I'd get movie tickets and they would organise outings for us. They took me out of my situation and gave me a little bit of respite. I got support through Carers Victoria up until Year 10. But then I dropped out of school, which meant I couldn't be part of the young carers program anymore. After that, I was moved to the Carers Victoria mental health team which gave me support, but not as much as the young carers program. Since the National Disability Insurance Scheme (**NDIS**) came in their funding is more limited so they don't support me as much. Carers Victoria were one of my biggest supports as a carer and now it's almost non-existent.

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<sup>1</sup> The name and details of the witness (and others) referred to in this witness statement has been changed to protect their identities.

- 5 FaPMI gave me a lot of opportunities both as a carer and a kid that has a parent with a mental illness. They ran programs over the school holidays for kids living with parents who have a mental illness to help us understand mental illness more. The programs are fun and you feel supported because everyone there has a parent with a mental illness.
- 6 FaPMI also gave me the opportunity to become a peer support leader. I have developed a voice because of the opportunities they have given me over the last six years. I have sat on panels and participated in a forum discussion with case workers and others working in the mental health system. I have a lot of connections through FaPMI and I'm going to look at becoming a facilitator for their programs.
- 7 It's been about six years since mum's first psychiatric admission and she's been in and out of the psychiatric ward over that time. Most of these admissions have been at one hospital. She has had a couple of admissions at another hospital as well. In different ways, there have been difficult experiences in both hospitals.
- 8 At the first hospital, the doctors often tried to discharge mum before I thought she was ready. I remember one time mum was in hospital for five weeks and I got a phone call late one night, maybe like 9pm, from her in tears saying, "*they are trying to discharge me tomorrow*". I just didn't feel she was ready to be discharged. So I called the hospital up and asked to speak to mum's doctor before he saw her the next day. I called on three different occasions that night and spoke to maybe three different nurses. They all said they were going to get him to call me back, but he never did. He ended up discharging mum that day.
- 9 The week before, in the last meeting mum had with the consultant, they were talking about doing electroconvulsive therapy (ECT). But the next minute they changed their minds and were discharging her. They wouldn't even consult with me on how I felt about it all, even though if she was discharged she was coming home to me. It seems to be a constant thing that there is no consistency in the hospital when it comes to family. The hospitals don't really like getting families involved.
- 10 There were multiple things that went wrong with that admission to the psychiatric ward. I spoke to one nurse about the admission. I was in tears and I told her that it was freaking me out because I didn't know what was going on. The nurse spoke to mum and I and treated us like people. She told us that we needed to put in a complaint about mum's treatment and talked us through how to do it. She had been mum's nurse and had put in referrals for an on-call doctor and a specialist for mum that never ended up happening,

although she didn't know that. The nurse talked us through how to make the complaint, and what needed to be in there.

- 11 When mum was admitted to a second hospital she took her psychiatric assistance dog (**mindDog**) with her. mindDog is a psychiatric service dog that goes everywhere with you, they're basically like guide dogs except they are trained for mental health. The staff in the hospital gave mum hell for it. She got a lot of dirty looks and then they said, "*Oh it's ridiculous that you're keeping a dog all locked up inside. This is not what a dog's supposed to do. Dogs aren't allowed in here.*" Usually when anything like that happens I step in and advocate for mum. When anything goes wrong, I usually get involved.
- 12 I am a big advocate for my mum. I have done it all my life. It was difficult when I was underage and lived at home by myself when mum was admitted. I didn't want to tell the hospital I was home by myself because I felt that it was going to get other people involved. I was fearful of telling them what was going on in my home life, or that I was home by myself. However, I think that either way, no matter what age, they've never listened to me. Unless I'm there in person, they never really listen to what I have to say.
- 13 Then again, it depends on which nurse you get. Some of the nurses I developed relationships with were really good, in particular one nurse at the first hospital mum went to is beautiful. She was one of my nurses when I was admitted there as well and she knows that I appreciate her. You also get some nurses in hospitals that don't care what you have to say as a carer. I have never had a good experience with the doctors because they never get me involved. They make it difficult for me to advocate for mum.
- 14 I know mum's mental illness well, better than anyone in the mental health system. I can contribute in terms of where my mum is travelling in relation to her illness. But the hospitals don't listen to me. I don't think they care about mum or about the family.

### ***Caring for mum at home***

- 15 I know when mum is having suicidal ideations, even though she is not articulating her feelings. In those scenarios, it my responsibility as a young carer to look after her and make sure she doesn't suicide.
- 16 A few months ago, I came home after a bad day at work to find mum in tears. Mum never cries. She is the type of person who will travel along silently until something completely breaks her, without telling anyone how she is feeling or what her suicidal thoughts are. I have suicidal ideations as well but I am open and honest about them and

I tell my case worker when I am not coping. Mum is completely different. I know that, I have learnt that.

- 17 Mum told me why she felt like that and I urged her to call the CAT team and admit herself but she didn't want to. Mum took some medication to help her through the night, but I had to take the keys to her medicine cabinet to make sure mum didn't overdose that night – that was my responsibility. I know mum's mental health, and sometimes I know what's going on more than the doctors do, but I am not asked my opinion or involved when she is in hospital.

## **My experience as a consumer of the mental health system**

### ***Child and youth mental health system***

- 18 My experience at the children's hospital I attended was usually really good. I was given the option of a bed in the psychiatric ward, staying in ED overnight or going home, depending on how I was feeling. They'd give me some medication, have a chat with me and usually I would either go to their psychiatric ward or I'd go home.
- 19 However, I had one bad experience where I went to the ED and told the doctor how I was feeling. He gave me no options and told me, "*there is nothing I can do for you, go home.*" I told him I was going to go kill myself and he didn't help. I got angry and walked out the doors by myself into the city and then, because I didn't know how to get help, I thought I might as well go and end my life. I was on the phone to mum because I was scared and wanted help, but I also didn't want to be in the world anymore at the time. I felt like the doctor had blown me off and told me there was nothing he could do. I told mum what my plan was on the phone.
- 20 My mum spoke to the doctor who had treated me and he said, "*she's left the hospital. There's nothing we can do, we're discharging her.*" The hospital didn't even call the cops. Mum had to call the cops to try and find me. I took myself to the North Melbourne police station, with a glass in my hand because I had broken a car window in a car park and handed myself in there.
- 21 A woman from the Police, Ambulance and Clinical Early Response (**PACER**) team came to the police station to see me. Even she told me that what the doctor did to me was ridiculous. After that, mum made a complaint with the Mental Health Complaints Commissioner.

### **Adult mental health system**

- 22 My first admission in an adult inpatient ward was in August 2019. I was there for two weeks. It was scary. I was 18 and everyone else was in their 20s, 30s, 40s and 50s. I was the youngest person there. I was there for my mental health and the majority of the people in the psychiatric ward were on drugs and coming off drugs. I felt like they were using the psychiatric ward basically as a drug rehabilitation program. Probably about half of the psych ward were drug affected.
- 23 I am a smoker so I used to go down to smoke with a few other people from my pod (which is like a ward in the psychiatric unit), who took me under their wing. We'd go down for a smoko, and we looked out for each other. But slowly, everyone started getting discharged.
- 24 I remember there was one smoko when all the people I knew from my pod had gone walking or on unescorted leave to the shops so it was just me sitting downstairs at 6pm in the dark alone, smoking. There were no nurses there, so people can do whatever they want. I saw some of the other inpatients do a drug-money exchange. It was scary. I went back upstairs and called my mum nearly in tears. I asked mum, *"Mum. What do I do? They're talking about drugs. They're saying that they've hit up, they've just done a money exchange. Do I go and tell the nurses or do I just leave it because I don't want to look like a snitch or a rat?"*
- 25 I was there for two weeks and then at 2 o'clock one afternoon I was told I was being discharged. I hadn't seen a doctor all day, discharge was thrown on me. That was so traumatic for me. I don't do well with change at all, and not instant change – I need a couple of days' notice. I told them that I didn't really want to go home to my mum as I was looking at moving out. Then they said to me, *"We'll put you in a motel for a few nights, we've pulled strings"*. I said to them, *"There's no point discharging me to a motel, you might as well discharge me to my mum's."* At about 6pm I ended up leaving the hospital. They sent me home in a taxi and not once did they contact my mum saying, *"She's coming home"* – I guess because I'm 18. The hospitals don't bring families into account and it's really frustrating. I was discharged on Friday, and the Saturday I ended up in emergency again.

## **Recommendations for changes to the mental health system**

### ***18-25 inpatient wards***

- 26 I think it's a problem that everyone from 18-64 years is in the adult mental health system. I believe there should be more 18-25 year old inpatient wards because then there are more like-minded people who share similar values. At present it's very scary for an 18 year old to be all of a sudden in the adult psychiatric ward with older people and people that are also coming off drugs. I see those older people and I think is that how I'm going to end up, with nothing to live for? It makes life so much harder.

### ***Accessing services to avoid an inpatient admission***

- 27 It is difficult to say how accessing services would avoid an inpatient admission for me, because I see inpatient admission as something that's going to happen. Although admission is sometimes not helpful, I don't necessarily see it as a bad thing. It's really hard for me to say what would make it better for me to stay out of hospital. There is support and services out there like Carers Victoria, however the services run from 9am to 5pm and I have school from 9am to 4pm, Monday to Thursday. So it's difficult for me to access and use these services.
- 28 In relation to after hours services, there are triage services, some of which have an online chat option. I prefer having an online chat option, because when I'm in a state I don't want to call up and talk to a stranger on the phone; I don't feel comfortable. I don't want to call them up and talk about mum because I don't want her to hear me.
- 29 I find the chat function really useful when I can get through, but I have a lot of trouble getting through. The one time I got through really quickly it was great, they couldn't give me counselling advice but they could listen and ask me questions which calmed me down and I got off that chat feeling much better. But every time I have tried to reach out since then I have never got through. When I'm feeling terrible and want to talk to someone, it's hard being told there are eight people in front of me and a twenty minute wait before I can get help.

### ***Responsiveness of CAT teams***

- 30 I think it would really help if CAT teams were able to respond without much delay. If I call the CAT team when I am in a crisis, they don't pick up their phone straight away and then I have to leave a message for them to call me back and it takes two or three hours for them to call me back. In that time period, I am already elevated, I get really

angry and make impulse decisions. I feel like I am done and I will often self-harm or sit outside in the middle of the road – I've done this multiple times. It usually escalates to cops and the ambulance coming to my house before the CAT team gets there.

### ***Developing trust with the mental health system***

- 31 A better response from the mental health system would involve more trust and less judgment. I have bad trust issues with the mental health system because I deal with judgment from them all the time and I don't want to be judged. For example, last month I got a new registrar who I see monthly. I was really open and honest with her that I use drugs because I am on medication. I wanted to know how to take my medication safely so I don't harm myself. This registrar said, *"That's not good for you. You shouldn't be doing that. You shouldn't take drugs. You're on medication."* But it is going to happen either way. I felt like the registrar didn't help and was being judgmental.
- 32 Trust has to be built between the adult mental health system and the consumers. I study nursing now so I understand where nurses are coming from as well. I don't know how to build that trust in the adult mental health system. In the adult psychiatric ward, they don't trust me. Maybe when I do a few admissions as an adult, they will start to trust me but at the moment, they haven't shown any trust in me. So I have learnt the system and I have learnt how to manipulate it and tell them what they want to hear. I don't tell them my plans honestly. For example, I don't tell them that I smoke, because I know that they would take my smoko off me. I can't deal with not smoking. I know it is bad and I want to quit but I can't at the moment.
- 33 However, I have experienced trust in the children's hospital. The staff at the children's hospital would take strict measures, taking everything off me including all my clothes with ties on them. But they'd communicate with me and say, *"This is what we're doing. This is why we're doing it."* I developed trust and understanding with them because I had been in there so many times.
- 34 Even if the adult mental health system is not able to build trust with the consumer, they should at least not be judgmental towards the consumers. In my personal opinion, nurses who are judgmental towards the consumers shouldn't be in that profession, they shouldn't be a nurse.

***Involvement of family in the care of the consumer***

- 35 The adult mental health system should involve family in the care of the consumer. The bad instances that I faced in the adult psychiatric ward were when nurses and doctors didn't understand what I was saying and didn't care about getting the family involved. They don't ask the patient if they want to involve family in the care.
- 36 This is very different from the children's hospital because they would involve my mum the whole time I was in there. We would have family meetings when I was getting discharged and the doctors would talk to my mum and me. But at the same time, if I didn't feel like I wanted mum involved, they would change it to how I felt comfortable.

***Differing needs***

- 37 I recognize that people with different mental health need different things. I haven't been in a Prevention and Recovery Centre (**PARC**) yet but mum's been in and out of PARC. There was one point in time when she was case managed such that she could go straight to PARC two or three times a year. She could just say that she needed to go to PARC and they would get her a bed. That's what she needed. I have not been to a PARC because that's not what I need. So everyone is different in what they need.
- 38 But there are things the mental health system could do better across the board. The psychiatric ward mum went to has a brand new facility which was built a couple of years ago. It's a great facility. They say they are going to run all these activities with the patients but they never did when I was there. All I had to look forward to when I was there was my smoko and sitting in front of the TV. There was one time when a peer support worker came in and briefly spoke to us there, but I don't really remember it. If I don't remember it and it didn't stick with me, it obviously wasn't that big of a deal.

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