

I am the carer of my 28 year old daughter who has a serious mental illness. She has experienced 9 admissions as a compulsory patient over 8 years ranging from 4 – 10 week admissions and always including a significant time in ICA and sometimes with seclusion. Admissions have been in six different hospitals. Over that time there has been great staff and good care but also not so good care and I have provided feedback on multiple occasions. The response to the feedback has been variable.

I am currently exhausted. My daughter has recently been discharged and is requiring significant support. The hospital has also breached confidentiality and this is the latest in a series of battles that carers are required to undertake to protect her (and my) rights and dignity. Unfortunately as a compulsory patient she is part of a system where there is no choice and you are constantly required to use a system where trust is difficult to maintain. On many occasions I just wanted to pick her up and take her to a different hospital. Unfortunately I have no say. This was confirmed to me when I protested against my daughter being transferred between three hospitals during one admission in 2018. From one ICA to the next to the next.

I had intended to make a formal submission with evidence of issues that she has experienced and suggestions for change but I have run out of time and energy. So instead I write the following about our experience and I am happy to answer any questions if needed.

Lack of beds

The most significant issue she experienced was due to a lack of beds and demand pressures. In one admission my daughter was

- admitted to ICA in [REDACTED] on 22 Dec 2017
- transferred to ICA in [REDACTED] a few days late
- on 1 Jan 2018 she was transferred to ICA in [REDACTED]
- and at 7.30pm on 9 January she was transferred to ICA in [REDACTED]

Each of these transfers was distressing and she had to be restrained and sedated to be transferred from [REDACTED]. It was acknowledged that these transfers led to deterioration in her condition and impacted on her recovery.

My daughter moved out of the [REDACTED] and [REDACTED] to a region with only one acute hospital so that this could not happen again.

She has also spent time shackled in ED with no beds available. Her longest stay in ED has been 16 hours which I acknowledge is not as bad as others have experienced.

Support when you need it

[REDACTED] and [REDACTED] are advertised as 24 hour services. This is not true. The only 24 hour service for people with mental illness is the police. I cannot count the number of times I have been told by [REDACTED] and [REDACTED] to ring 000 if I cannot manage. I find this appalling. We are asked to rely on the least trained part of the system when our daughter is at her most unwell. While we have only experienced compassionate police [REDACTED]

[REDACTED] I do not plan to ever ring police unless I am with my daughter at the time to ensure her safety. This significantly limits our ability to get care when my daughter has no insight and refuses to attend ED.

The staffing of triage is also an issue with staff not sufficiently experienced or willing to listen to carers. I have been refused [REDACTED] due to my refusal to put my daughter on the phone when I have explained that she is a significant flight risk. Given the issues we have involving behaviour that puts her at extreme risk I need to be able to get help when she is unwell without her agreement.

A rigid system

The current area based system is rigid and not person based. My daughter has now been a client in three different areas so we have also experienced how different areas work. She first moved out of home to a different area in December 2016. I requested that she keep her current case manager while she settled in to her new place and over Christmas and New Year when it is well known that services are limited. This was not allowed and so she met a new case manager at a new service on 23 December. Needless to say we had limited access to support over the New Year when she was becoming unwell.

All my daughter's admissions have been traumatic. However, she has had very poor care in one particular hospital where she has been admitted twice and never wishes to return. Unlike other sick people who have some choice my daughter had to move out of the area to avoid being admitted to that hospital.

At one point my daughter was not attending her community appointments. I found in the rubbish a note to her saying if you don't attend we will discharge you. My daughter was happy as she did not like her case manager. However no one had contacted me (who she was living with) about how things were going. I contacted the case manager and was told they can't keep her on and waste the appointments so they planned to discharge her to her GP. As she did not have a GP I had to find her one, and a psychiatrist who would take her on. This arrangement was not successful and she ended up back in hospital. The psychiatrist kindly explained that the private system is not suitable for someone like my daughter.

Back at that time it might have been possible when my daughter was more well than now, for her have a good GP with support from a psychiatrist. Unfortunately in the current system there is no middle ground. Either you are a community client with a case manager and psychiatrist, or nothing. There does not appear to be an out-patient type model where you have a GP who can then access public psychiatry support or know that their patient will have regular psychiatry review. I know of people with epilepsy who have a GP but attend a neurologist in public outpatients each 6 months. There is nothing similar for psychiatry so people who may possibly manage with a less interventional model are not supported.

Unfortunately my daughter would no longer be suitable for this model of care.

Another issue is that a person may need a range of services for their condition. It has been recommended that my daughter access counselling/psychology to work with her on management of stress and trauma. To do this it has been recommended that she see a GP and get a mental health care plan to access subsidised therapy. This sounds a good idea but so far we have not been able to manage to do it. She has to have a GP she can confide in and then we will need to find a psychologist with the necessary skills and willing to bulk bill. This is all too hard. On three occasions the [REDACTED] [REDACTED] I have suggested she access the [REDACTED] for support including counselling. I cannot even think of facing the [REDACTED] paperwork with my daughter who is distressed even reading reports written for her [REDACTED]

Compulsory care

My daughter receives much of her care while a compulsory patient. I am her nominated person. We have attended multiple hearings. Some are very compassionate and respectful, others ok, and occasionally patronising and hurtful. This appears to have been person dependent but it does not help us trust the system or encourage us to participate fully.

On occasion I have been acknowledged by the panel as a nominated person and a mum and the tensions that this can sometimes lead to. I have then been given the opportunity to speak as either

or both. However at other times I have been asked bluntly – do you think your daughter should be on an order?; is your daughter as well as she can be today?; do you have a proper plan in place if she is unwell?. None of this assists with the fine balance that carers walk with the person they care for.

Hospital reports to the tribunal are an enormous stress for my daughter. They are often confronting and also often wrong. We have tried over years to ensure that they are correct but unfortunately once something is written in a file it becomes the truth and is perpetually included in reports. We have now given up and are happy if a report is generally correct. I was told by one psychiatrist when I asked for a report to be corrected 'would it have made any difference to the outcome?'. I didn't bother any further and the errors were in the next report. My name has not been correctly spelt for 8 years and I have not been able to resolve it.

We have only attended one tribunal for ECT and it was not approved. My daughter is adamant that she will never receive ECT and as her nominated person I support her. However a treating team had previously told me that the tribunal would be unlikely to go against the family so it would be best if we supported it. This was terrible pressure when my daughter was so unwell. Fortunately I received independent advice that my role was to support my daughter and the treating team's role to demonstrate the need for ECT.

I am not sure what could replace this compulsory system. I understand in other jurisdictions it is not used as much as in Victoria. When my daughter is unwell she needs compulsory care. When she is better the orders are meaningless and do not keep her well.

In hospital care

Unfortunately my daughter is only in hospital when she is extremely unwell with severe and prolonged manic/psychotic relapse. She has had very caring doctors and nurses during some admissions and I thank them.

However admissions to hospital with ambulance and police, long periods in ICA, times in seclusion, code greys, and multiple injections against your wishes is traumatic. I spend time with her everyday but it does not relieve the trauma and distress.

Over time she and I have experienced large variations in care in different wards. In some she is treated with respect and in others I have been told that she is in seclusion because of her 'bad behaviour'. I don't think some staff are aware of the effect their words can have on already distraught families.

On many occasions she has been put in ICA without my knowledge as her nominated person.

My daughter has been in ICA without access to a phone. The hospital phone did not work and patients were not allowed to have mobiles. Access to communication when you are unwell is critical.

I have stood in the corridor of a ward and cried and been ignored by staff.

I have attended a family meeting after not being able to speak to a doctor for the one week she had been in hospital (in ICA). It was attended by a registrar who had never met my daughter. She provided a new diagnosis (second hand from a consultant we never met) and said my daughter would be discharged with anger management. My daughter was transferred two days later and we were told how very unwell she was.

That hospital apologised for the family meeting and that they would learn from it and not have the situation of a registrar attending who had not met the patient again. The next time my daughter was admitted to that hospital they didn't have a family meeting nor did I ever speak with a consultant despite time in ICA.

Conversely, in some ICAs patients are allowed to have their mobile phones. This is a significant issue and needs consideration. Phones are now not just phones. They are also access to the internet. My daughter posts things on social media that she later regrets. This is a significant reputational issue and impacts her ability to maintain friendships, accommodation and occupation. Phones can also record and take photos which again can be posted on line. I am concerned that if you are unwell enough to be in ICA then maybe you should not be posting on social media.

My daughter has been asked to elect to be a private patient while she is in ICA and quite unwell. She signed the election form and it was witnessed. I was told that she had understood what she was doing which was not the case.

My daughter has been given the wrong dose of medication three days in a row before it was noticed.

I have been told that my daughter was escorted to ICA without physical contact but she has shown me the fingerprint bruises on her arm.

In one admission you would ring the bell for admission to the ward and be left standing for up to 10 mins with no response. In that ward if you knocked on the window of the nurses' station to be let out or to ask a question you would get 'the look'. Here she is again.

I asked once as I walked into the ward how is my daughter today? and the answer was I can't hear her yelling at the moment so she must be ok.

Privacy and confidentiality

My daughter is entitled to her privacy and so am I. I have long come to terms with the fact that all my family business is shared with others when my daughter is unwell – in the ward and online. However this does not excuse the often poor care taken with information I have provided in confidence to support the care provided to my daughter.

Carers walk a fine line working with hospitals and case managers with the permission of the person they care for. At times it is necessary to cross the line to ensure the safety of my daughter. I have been promised by [REDACTED] that information won't be passed on, only to have an admitting doctor do so. Or have a doctor tell my daughter that I am in agreement with the medication she is on when she does not want me involved. It is very difficult to maintain a relationship at these times.

Recently very personal information provided to a case manager to assist with a treatment plan has appeared on a discharge summary. I am in the process of trying to sort this out but it has significant safety ramifications for my daughter and I.

Complaints

Complaints handling is variable. I do not think services understand that carers are often at the end of a series of issues before they actually complain and that it is much easier to let things go.

The first time I ever put a complaint in writing I received such a defensive reply that included justification of their decisions and incorrect information about me that it caused me more distress than the original complaint. I decided then that I did not want this to happen again so I would only provide verbal feedback in future. However I have found these are rarely recorded or acted on.

I am told that issues will be investigated but rarely get the feedback I have been promised. I have recently written again but not received a reply.

Social and economic participation

After my daughter first became unwell she was able to complete a TAFE course and gain casual employment in a hospital. This was great as she had tried to return to university but found it too difficult.

When my daughter next became unwell she was admitted to hospital and was not able to work. She was contacted while in hospital to say that she had not done enough shifts and was no longer employed. She was admitted at and worked for the same health service. This was disgraceful and very distressing. Fortunately the decision was reversed when we spoke with her manager about the issue of sacking people on sick leave.

When my daughter did return to work she was asked for a medical certificate which was supplied. However they just stopped giving her shifts and she has not worked since. They had previously said that she was good at her job and a good worker.

This year she enrolled in a course at a local college but has had two admissions to hospital and the teachers have said that she cannot return due to her health issues. And that she cannot reapply in the future. We will try and work through this with the college. I acknowledge that it would have been difficult when she was becoming unwell but I do not think that their decision should be absolute. But it is hard to maintain enthusiasm when you have been told you are not wanted.

Accommodation is a big issue. My daughter has not lived at home now for a couple of years but has struggled in share houses. It is impossible to afford accommodation on your own on the [REDACTED]. We have managed to find a suitable unit by me also being on the lease but this is not a viable long term option when I not in the workforce. She was referred to a [REDACTED] for support but they are unable to assist as they have said she is in stable accommodation.

I understand their position as there are people without a home at all but wouldn't it be great if she could get assistance to plan for accommodation that is long term, affordable and stable to assist with her mental health.

Carers and families

We live a difficult life but not as difficult as the person we care for.

It would be great if the system did not make things more difficult.

You don't ever get used to the trauma and grief.