Annexure to original statement 587
Carer for Anonymous

After the Mental Health Review Tribunal, I sent a letter expressing my disappointment with the disorganised way hearing was conducted. While they did acknowledge that the lack of organisation fell short of the standard expected, they denied it was disrespectful to my friend.

My friend was placed on a 6 month CTO at the beginning of November 2019 upon their release, where treatment consisted of 400mg Abilify Maintena once a month, however as my friend began renting privately, their community centre was changed as it was in a different catchment area. At this community centre, they are seen once a week by a psychiatrist, but the same psychiatrist cannot be guaranteed. While it was a pleasant surprise they could get specialist help regularly, it would be helpful to know the catchment boundaries for purposes of renting, and it would be much better to have one psychiatrist instead of whoever is working so both patient and psychiatrist can build rapport.

They did not receive a varied CTO upon changing, so we asked for it, and it was provided after some time. I noticed that the names of the treating team differed to the ones my friend had mentioned, so I called the case manager for my friend to clarify. The case manager was abrasive and told me that the only thing I needed to know was that if my friend breaks their CTO they go back into hospital. I patiently explained that the patient has the right to know who is treating them and if the information is right or not. The case manager then told me that there is an intake team, which is changed to a regular team. I don't understand the reasoning behind this, but at least we received some sort of response. However we should not have to push for this information, and I feel the case manager is unprofessional. We should not be experiencing opacity when the goal is to improve my friend's mental health.

Around this time, someone who was in the inpatient unit with my friend attempted to access my friend's iCloud. We knew who it was immediately, as there was only one person whose phone my friend accessed to look at their bank account and eBay. I complained to the nursing unit at the time because my friend was not allowed to have their phone or access the internet while in the unit, and I was told they can't control what people do, and I should not blame this person for enabling my friend. I understand the unit may be short staffed but I have also observed there seems to be a toxic workplace environment between staff members from the way they operate, the way they speak to each other and to visitors and especially to my friend. Their body language overall is poor and are cagey in their interactions instead of open and friendly. Yes, dealing with mental patients is hard but there is no excuse to take it out on visitors and patients.

We visited the medical records office to pay the remainder of the fee for the records in mid November, as there were approximately 850 pages over numerous visits. Instead, we were handed a small file of discharge summaries and when I queried as to where the remaining pages, we were told that my friend had agreed over the phone they no longer required the medical records in its entirety and that the discharge summaries were sufficient. I pointed out that we have the discharge summaries from the GP's medical records, and that it is written on the form that the records in its entirety is requested and it is signed. The officer then told

me that what would I know since I haven't seen nor signed the form. I told her that I saw the form, helped my friend fill it out and we signed it together! She then said that a lawyer would need to request them and they would be redacted heavily. When I took the records home to compare what I had, they had missed out a summary. This deliberate obtuseness makes me think the treating team have written things they don't want us to see, and that they are hiding behind this privilege. If we don't have access to my friend's records, we don't know what has been happening so we find it harder to plan our way forward in terms of treating my friend's condition appropriately. It is also unethical to deny patients to their records.

Their upcoming court case was quite stressful, and my friend against the wishes of their lawyer and obtained a report from a forensic psychologist they did not work with at the cost of almost $2,000, not rebatable, but could finalise the report by mid December. The forensic psychologist the lawyer works with could not get the report done until the new year, but was $900. The lawyer examined the report and said that it wasn't written in the way he would have wanted to give my friend the best chance at another section 32. When we heard the decision, my friend did not get the second section 32 as the Magistrate said it was important that the sentence serves as a deterrent for the future. He said he took into account the fact that my friend's mental health treatment over the years was insufficient. He also commented that the application for the section 32 was more genuine than other applications he had received, and that my friend exhibited a genuine desire to do and be better.

My friend's Medicare card stopped working so they couldn't get a rebate for a few services, including a psychiatrist's appointment costing over $400. I am named on the Centrelink account, so I enquired if it could be looked into, only to be told smugly by the Centrelink manager that they had to do it themselves as the Centrelink authorisation is not the same as the Medicare authorisation, and I also had to be added to the Medicare contact list as apparently it is separate from the Centrelink list. He also told me that if I complain he doesn't care. There needs to be proactivity from Centrelink staff to ensure if someone is named on one account that the patient and carer are given the option of adding the carer to other accounts.

Also during the month of December, I contacted the Royal Australian and New Zealand College of Psychiatrists to obtain discharge summary guidelines, as a number of people told me that the information contained in the latest discharge summary was not just incorrect but unnecessary. I feel it was written in a derogatory, biased manner, and overshared information. The RANZCP to date has not provided me with this information despite assurances. In this way, it is protectionist of the profession rather than holding their members accountable for their actions. I feel the aim of writing the discharge summary in this way was to direct my friend into the criminal justice system, coupled with the lack of social work and insistence that my friend do brain scans at the hospital 'to help with their court case'.

Over December 2019 it became clear that the dosage of Abilify was too strong as they began complaining about chronic insomnia. Instead of varying the CTO and admistering a lower dose of Abilify at the scheduled time, the psychiatrist prescribed olanzapine, with the words 'take 5-10mg at night' and another note on another envelope reads '...Seroquel… for

insomnia'. I am shocked that a medical professional would do this; yes olanzapine would provide much needed long sleeps for the patient, but it also is notorious for patients gaining weight and my friend is already on a strong antipsychotic as it is.

I went away on holiday for a month over Christmas, so I was not able to keep a close eye on my friend. Instead I sent an email to the case manager at the community treatment centre looking after my friend with a number of requests. I received no reply. The email states

Hi x,

I hope you're well today. x is due for their depo today at 11am.

They've raised a number of things they would like to talk about either today and with the psychiatrist next week on 23/12.

Magistrate x mentioned during the hearing that it was important that x receives holistic care to prevent reoffending. In saying that:

1. x has gained a significant amount of weight over the time they have been taking Abilify with Epilim in high doses. We are worried they will be classified as obese soon as this causes its own problems such as diabetes, pancreatitis, DVT like symptoms, high cholesterol and so forth. They are not able to afford to treat any of these conditions. Is it possible they can see a dietician who can recommend a diet that can eliminate further weight gain. They are depressed because they are now grossly overweight, and does not have the energy to exercise on their current medication combination.

2. Following on from this can they see an exercise physiologist to devise a weight loss plan.

3. Can they see an endocrinologist to ensure they are not developing endocrine issues that may be typical of rapid weight gain associated with psychiatric medication.

4. Can the psychiatrist revise the dosages of the medication they are taking as we feel 400mg Abilify Maintena per month is not suitable to their current situation. I understand 300mg is available.

5. They have been asked to cease alcohol consumption. Alcohol consumption is a comorbidity of mental health patients and as such is not easy to go cold turkey on something that offers temporary relief from life's troubles. Could you please look into a program that deals with this and in conjunction address the balance of medication?

6. I am away overseas 21/12 to 11/1. Christmas is a particularly sensitive time for mental health patients due to isolation. Could there be a plan put in place to ensure their wellbeing over this period.

7. We are in the middle of applying for NDIS. Their GP has filled out a form and his social worker at x has advised the second form should be filled in by their psychiatrist. Can we get

the second form filled in on 23/12 so we can file in the New Year. The psychologist, x, who did their court report has recommended that this is a priority to assist them in social supports. The form will need to address both their psychosocial condition and their bladder dysfunction. They are also not able to cook for themselves as it takes too much energy buying groceries and cooking, so they have takeaway, which is expensive and unhealthy. They are not able to clean their room, and finds it hard to wake in the morning and form a routine. They find it hard to do laundry and self-care (showering, shaving, self-catheterisation which leads to UTIs).

8. Can we arrange for regular psychological appointments. Their psychologist x has offered to be the ongoing contact for this. They have a current mental health care plan that expires mid March 2020. Please let me know if you need it. Furthermore he may benefit from dialectical behavioural therapy to manage their emotions effectively. This should be covered by their health insurance. There are programs at Northside, St John of God Burwood and Hills Clinic.

9. We will be doing a risk assessment for x should they need to go into care if they feel unwell. Please do not put them into x as they were been given prejudicial treatment due to the nature of their court case, and I do not want them to be subjected to more of the same as it is bad for their mental health. They need a safe environment.

10. X has an issue with their Medicare card at the moment. We will be fixing this tomorrow.

11. I have received a notice from Centrelink advising they need another medical certificate to be exempt from looking for work so that they can keep receiving payments. Can this be done today so we can take it to Centrelink tomorrow?

12. Can they please see a financial counsellor to help them budget. They do not know how to budget as they previously earned good money. X at x has offered to see them provided they make an appointment.

Please let me know by email what can and cannot be done, as x will not be able to remember everything. Also, please make sure they put all their documents into a plastic wallet I have given them so they are not crushed.

Thank you,

X

I understand that Seroquel is also prescribed by general practitioners for anxiety purposes. This is also shocking as prescribing an antipsychotic that is associated with a long list of side effects is prescribed medium to long term to general members of the public simply because they cannot sleep. In addition to my friend constantly complaining to the psychiatrist they cannot sleep, they visited the GP who prescribed them benzodiazepines (again!).

Unfortunately my friend packed on 10kg within a month. They came to see me after having an interview, and planned to go out to dinner. Unfortunately when they sat down on my couch, they ripped their work pants at the crotch. I noticed that their stomach was much larger than the previous month and that their thighs had increased significantly. We cancelled going out and ordered takeaway. They began to panic, saying they needed the pants for another interview and could we get them mended. I reassured them that of course we could.

I began doing some more admin work for my friend and called NCAT, who had not responded to our petition for guardianship. The application had not gone through as one of the email addresses provided for NCAT were not included in on the email. We since have received a listing date of 1/4/20, but this is too far in the future. I was also told I had to obtain a filled in form provided on the site from their GP to state his level of capacity. These oversights have disadvantaged my friend, as lack of guardianship means it is difficult to get anything done. As of the second week of February, his GP has refused to fill in the form that we need to send to NCAT within the 21 day time period, because he does not agree with it. Therefore, my friend will be limited in the help and the speed of it they can receive from me. This disadvantages the patient as we do need a complete picture of what has been happening in the last seven years, what has been done and tried and what has and has not worked so we can plan for the future.

I also got in touch with Housing NSW, who explained that because the last piece of documentation my friend was to provide was on 21/1/20, this is when he is placed on the waiting list for accomodation. We were never told at any time this would be the case, as his initial documentation I believe was supplied in August 2019. This lack of information has disadvantaged my friend. They have been asked to move out of their current share situation in 3 weeks' time as the owner wants to renovate (nothing to do with my friend themselves).

The initial problem is when we went to X Community Housing in November 2019, we were advised initially that the wait list for catchment Y is shorter but my friend would be out of area and not priority. We took this advice and nominated it. We were also told we could not nominate a second area. When I raised the issue of no medical and no social support available in the area, there was no comment. The other problem is that when I rang in January 2020 I was told this area is wrong, because he should be placed for priority in catchment x, as their CTO was listed as in this area. When I rang X Housing, which is taking care of this area, they informed me it is mainly accommodation for over 55s and rarely does a property for someone of my friend's profile come up; the wait list is 2-4 years even as priority. None of this was communicated to us by X Community Housing as apparently they did not know; I had to ring up myself and even then it was hard to get the information out of the person answering the phone.

I contacted X Community Housing again and asked if the area my friend had moved was a different area, and X Community Housing didn't know that they had moved, but then again we were never informed we needed to tell them as we didn't know about catchment areas. I had no idea that housing was decided on the basis of residential address, treatment and ties

to the area, and so when we asked for the catchment they were living in we had to provide evidence of a CTO being administered in that area, so this was provided to Housing NSW and they were placed on the priority list - thank goodness we asked for a varied CTO last year and were provided with it. Catchment areas make it difficult for patients to access help, as information is not communicated at all about what is required to be placed on the wait list, when it starts, where catchment areas begin and end (apparently catchment Y is looked after by Housing NSW and overlaps with catchment X depending on the suburb), catchment wait times as they are different etc. It makes applying for housing extremely time consuming and difficult, and my friend is not getting the help they need to stabilise their condition through stable accommodation. The other issue is that they were not able to access the remaining 26 days of paid for accommodation as they had more than $1,000 in the bank. We said most of the funds are for legal fees and medical expenses but we were told it might be considered if we provided tax invoices etc. We decided it would be too hard and so did not bother. This again disadvantages my friend as it meant he was in an unstable position - two days to find a stable place is nowhere near enough.

I next met my friend when I came to their place to do some of their administration work, and observed that their room smelt stale, littered with empty and partially food and drink containers and that nothing in the time they had been renting their room had been put away. My friend was dishevelled and had not showered. Nothing had been laundered; they had been using the same few clothes for weeks. I put all the trash in the bin, and laundered the clothes and the bedding, which was dirty as well. Before they started renting again, I emphasised the importance of keeping themselves hygienic and their room tidy. The homeowner came home early, and I explained to him my friend’s condition, what the medication did to their body and why they had limited energy. It was difficult for them to understand in the beginning, but I answered all their questions and gave them information on how to manage them, and I felt they had a great deal of compassion. I felt that my friend was lucky to have such a landlord, as most people are not as accommodating. This is why I am upset their case manager at the community centre has not been proactive in doing the social work necessary for my friend.

I wrote to the case manager again at the end of January 2020.

Hi X,

X's tried to get back in contact with you re the medication they are meant to pick up. Can you please give them a call.

I'm not sure if you read my email but since they have been prescribed olanzapine they've gained 10kg and they are busting out of they clothes and I did ask for a weight management plan to prevent this from happening.

I know they have sleep problems but prescribing Seroquel and Zyprexa in copious quantities is a band aid solution. Can we look at reducing the Abilify to 30mg?

Have you been able to do any of the things on the list, as their NDIS is still not filed and they needs it; I have had to do their laundry and clean their room as they are unable to do so. With NDIS someone can do this professionally. It is also hard for them to make calls to get things done and to go places that is not Ryde, as they are exhausted much of the time.

I know you don't want to talk to me, but if you said a phone conversation approved by X is enough to establish I am their carer then you need to pay attention to their wishes - they don't want to gain any more weight.

I have been told you can do all of the things on this list by other organisations so I don't know why none of them have been attended to.

X

I spoke to the case manager following this, where I voiced my concern that my friend had put on a lot of weight and that can we ask to reduce the Abilify administered. I also asked for the form to be added to my friend's record. I was told that they can come and they will do it together, but we've been through this excuse before at the hospital, which is another way of saying they don't want to do it. I also said he had not done any of the things I had put in points for him to do. He told me that my friend had not asked for any of these things and that they need to ask. I said they shouldn't have to ask and as a case manager they should be proactive. I said that because NDIS still hasn't been filed with the additional form from the treating psychiatrist at the centre, my friend is still at disadvantage, doesn't eat regularly or home cooked healthy meals, still has to pay for catheters, and still lives in squalor. NDIS funds assists with all of these things, and was recommended in the psychologist's report.

The case manager said they were upset because my friend won't take their calls, and I said it's because they don't like taking phone calls and to text or email them. I also said it's important to call later in the day, not in the morning as they don't wake up early enough. The case manager then got upset and said they were ending the call as they don't like being abused. I said it's not abuse to point out their lack of interest in my friend's wellbeing and to forward the form to me to fill out and have my friend read it and sign it. They said they would need to copy the form and email it and could they have my email address. I said they've got my email address (makes me suspect this person deleted my emails) and emailed, staying on the line to make sure they received it. I have no idea why there is no electronic version of the form available to them, and I am not sure if it was done on purpose or if the case manager is incompetent, it was the standard NSW Health request for medical records form, found on their website. I have found the relevant form and have filled it in. The case manager has emailed me before without difficulty, so I am wondering what the panic and accusations are about. They also said for us to meet with them. My friend has said that the case manager has asked them to meet for coffee on a regular basis, and that they have found the weekly meetings useless.

Following this conversation, my friend told me that the case manager harassed them with multiple phone calls. They also told me that the people at the centre don't like me and I simply said that is because they do not like being questioned.

I think anyone reading this can agree that the care the community centre has provided is substandard and also does not meet the conditions of the centre's obligations as per item 4 of the CTO provided which are:

- Provide support and assistance with x's goals of recovery including x's mental wellbeing
- Monitor and provide education regarding mental wellbeing and ill health and how x's experiences impact on x's life and functioning, including x's family where appropriate
- Ensure that x is aware of his rights of appeal and rights into seeking revocation or variation of the community treatment order
- Provide an initial appointment for assessment with the treating doctor on Thursday 5th December 2019 at X Health Centre)
- Facilitate the effective implementation of the community treatment order by arranging and supporting effective communication between x, x's nominated carer under the MHA, x (case manager), and Dr x or Director of Community Treatment at X Mental Health Service.

As far as I can see, only point 4 has been completely met. I do not believe that my friend has been provided with any support or assistance from their case manager, despite numerous things that need to be done to ensure their mental health and wellbeing. They received daily calls from staff over the Christmas period, but has never been educated on how ill mental health impairs their daily functioning and relationships with others, has never been informed of his rights of appeal, and that has never been communicated to or with in a way that is most effective for them, in that things must be written down instead of verbal, that they prefer text and email over phone calls. In this respect, it is discriminatory if their wishes on preferred communication methods are not adhered to.

As of mid February 2020, my friend has been diagnosed with insulin resistance, so we have to start managing that. They have independently seen an endocrinologist who recommended a diet plan, and that they have low hormone levels, and has let them know that this is the result of this cocktail of antipsychotics. They have received two job offers for $60,000 plus super each, interviewed for a role worth $110,000. But will the community centre come to the party and ensure they can keep their job? Their case manager said that they would be able to receive their depot on the weekend, but I doubt this. The job they want is in a different catchment area, where they received their initial CTO treatment, so hopefully we can push for the depot to be administered there on their lunch break. Or will the current community centre try and keep them in the poverty trap of poor mental health and physical health with substandard service? Only time will tell.

To be continued...