

## **The situation**

I am a carer of my son who has a complex mental health condition. My son is in his 30s and has a Doctorate. Prior to his illness my son worked as a Lecturer at University and consultant in a variety of entrepreneurial ventures. My son had his life pretty well mapped out for him. He was on a trajectory to lead a rich and fulfilling life with a partner, social network, an excellent job and career prospects and contributing to the broader community with a number of social enterprises.

My son's first episode of mental illness was 2.5 years ago with no signs, symptoms or mental illnesses prior to that episode. My son has had at least five different diagnoses since that first episode, with the current diagnosis bipolar one disorder. Since his diagnosis, my son has had recurring episodes of psychosis and difficulty stabilising on medication. He frequently does not seem to have the balance of medication required for him to function 'normally.' He often appears to be overmedicated and finds difficulty getting motivated. Some of his prescribed medications have significant side effects such as weight gain, damage to liver and thyroid function. Last year my son spent 4 months in hospital care over a number of episodes and hospital admissions. He was scheduled three times in order to get the care he needed.

My son is unable to resume his previous life. Initially my son managed to work part time teaching online but with 4 months hospitalisation at different intervals last year he has been unable to hold down a job. He has applied for at least 25 jobs. He has currently submitted two applications for jobs. My son has to totally re-invent himself. He currently has no professional help with this journey. He moved house to a different suburb and because of this now comes under a different community mental health team. He hasn't received any help from this new team. He is currently unemployed and over-medicated.

My son has had a serious setback to his life. My son and all of us close to him are in the process of adjusting to my son's mental health condition and the impact of that on his future. My son has lost a great deal of what he had prior to the condition including partner, job, income, some friends and the career prospects he had. My son and all of us around him are on a journey to help my son re-invent himself and resume a rich and fulfilling life. My son in particular, and we who support him cannot do this alone. We need a strong, well co-ordinated team around us. We don't have this. We feel very much alone on our journey.

Considering the high financial costs of hospitalisation, the high risks of danger to self or others in an acute psychotic episode and the devastating trauma to my son and all of us who care for him when he's in an acute episode I'd like to make the following suggestions in regard to gaining early treatment for symptoms of psychosis, keeping people functioning in the community, averting an acute episode, reducing risks of self harm and harm to others and reducing financial costs associated with hospitalisation. The suggestions include:

- A dedicated holistic community-based model for managing people with complex mental health conditions
- Provision of community-based services for early treatment of symptoms of psychosis and maintenance in the community
- Improved availability of, access to, experience in, resourcing, goals and outcomes of hospitalisation.

## **Dedicated holistic community-based model for managing people with complex mental health conditions**

There needs to be a separate dedicated framework/model for the management of people with complex mental health conditions in the community. The model needs to cover early intervention, treatment of acute episodes, recovery from episodes and rehabilitation to be able to lead a productive life in the community. Continuing support may be required for years to keep people out of hospital and living successfully in the community.

This model needs to be adequately resourced and funded and key stakeholders trained to implement the model. The core of the model is the community mental health team which is a one stop shop focusing on keeping the person stabilised and episode free and supporting the person through their recovery to lead a full and productive life in the community.

The community mental health team needs to coordinate the individual treatment, recovery and rehabilitation programs with the person with the condition, their family/carers, the GP, health professionals as appropriate and the psychiatrist.

The model needs to include:

- A holistic approach to treatment where health professionals such as psychologists work with the person to develop and help implement a plan involving other health professionals as required all working together
- Community mental health teams funded on the basis of providing total packages of health care, treatment and rehabilitation to individuals and groups of people with complex mental health conditions assisting them to lead full and productive lives
- A treatment framework/package (and funding model) for GPs to service people with complex mental health conditions with the goal of coordinating services and maintaining the person in the community
- Involvement of families/carers in treatment and rehabilitation
- Training and liaison with local police.

## **Provision of community-based services for early treatment of symptoms of psychosis and maintenance in the community**

In my experience from the initial episode to multiple subsequent episodes, it has been impossible to gain any treatment for early symptoms of psychosis, that could have prevented police involvement, and my son being scheduled several times.

I'd like to make the following observations in regard to accessing early treatment for symptoms of psychosis. Generally, the initial contact for treatment of symptoms is the GP. People with complex mental health conditions need a regular GP. The GP needs to recognise symptoms of psychosis and that invariably the person needs admission to a mental health institution. The GP needs to involve the family or carer. The GP needs to do everything in their power to get the person to hospital care. The GPs should work very closely with the community mental health teams. In my experience they have never worked together. Ideally the GP could be the case manager for ongoing care which in the case of complex mental health conditions is likely to be the rest of the person's life. The funding model needs to provide financial incentives to GPs to have people with complex mental health conditions on their

books on a regular basis, to maintain them in the community and reward them for achieving outcomes with the person like lifestyle changes such as weight loss, improved fitness, giving up smoking or alcohol or substance abuse etc.

### **Improved availability of, access to, experience in, resourcing, goals and outcomes of hospitalisation**

My understanding (and experience of one) is that people with symptoms of psychosis need hospitalisation for stabilisation on medication associated with recurrence of symptoms of psychosis. In my experience, my son didn't have insight into just how seriously ill he was and he was delusional so he didn't think he needed to be in hospital (and certainly didn't want to be there). It would have been very helpful for us if the community mental health team, the GP or the psychiatrist, all of whom my son was familiar with and had some level of trust could refer him directly to the mental health unit in the public hospital where he could be assessed and admitted if needed.

Hospitalisation in the high dependent locked ward of an acute mental health unit in a public hospital is extremely traumatic for the person and their families and friends. We have now been involved with admissions to three different hospitals (apart from private hospitals). My son has been extremely traumatised by admission with police escort (twice), forced injection of medication, fear of symptoms, having everything that he knows taken away from him, being incarcerated in a locked ward with other people similar to him.

In my experience with each hospital, the staff are located in a locked glass office area and the patients hover around outside the office trying to get access to see their doctor etc. It is very difficult to get access to staff. Families are generally not consulted. We have had to fight very hard to be heard at all. Neither the patient nor the family knows what's happening with the treatment plan or even if there is one. The goal of treatment appears to be to get the patient stabilised on medication and discharged once they're stabilised (generally about 9 days). On the eighth day there was a meeting with psychiatrist, patient and carers and everyone told the patient will have a trial staying at home tonight and if this works they are discharged home unwell and with little or no ongoing treatment plan.

Acute mental health wards in public hospitals appear to be insufficient to meet demand, under-resourced and unable to do anything else but 'stabilise' the person on medication prior to premature discharge. There does not appear to be any ongoing treatment plan for recovery and rehabilitation in the community beyond referral to the community mental health team.

We value the opportunity offered to the Productivity Commission with this inquiry. We are happy to contribute in any way to help ensure the outcomes meet the needs of all of us who struggle in this domain. Thank you for the opportunity to make a submission.