## The social and economic costs of being diagnosed with Bipolar Type 1 as a 32 year old full time working professional male

I would like to thank the Productivity Commission for the opportunity to respond to the issues paper. I am a professional working in financial services and am submitting my experience as a informal carer with examples of the social and economic cost of psychosis.

My husband, also aged 32, was diagnosed with Bipolar Type 1 in 2018 after experiencing two episodes of psychosis mania within a month of each other. The first while travelling overseas, which was incorrectly diagnosed when we returned to Australia, and thus another severe mania episode occurred shortly thereafter. Both episodes required hospitalisation of a few days. His diagnosis was also missed 10 years earlier when he suffered a more mild manic episode at aged 22.

Prior to our holiday which triggered this, he worked as a full time public servant in shift work ranging from 5am til 11pm. We had very active social lives and considered ourselves very active members of society and in regular social activities with friends.

To outline the real economic cost of our experience:

- Our travel insurance covered the disruption to our holiday as there was no previous diagnosis, and totalled \$3,400 in lost accommodation, flights and pre booked activities.
- The initial sick leave my husband required totalled 2 months and essentially depleted all sick leave he had acquired. The value of this was approximately XX
- The carers leave that I took totalled 3 weeks at a value of approximately XX
- Upon discharging the mental health hospital in Sydney it was recommended my husband not return home immediately, but spend another week in a low stimulating environment (there was an option to remain in the facility but he did not want to do this and we did not want to have him forcibly admitted). To find a suitable balance of a low stimulating environment, we stayed in a waterside apartment for a week at a cost of \$3500.
- My husband will not be in a position to return to full time work until about 1 year after the
  initial episode, and is currently working 3 days a week. This is to support him as he recovers
  from his episodes and as he adjusts the dosage of the medication downwards over time. His
  annual income full time is \$60,000 plus shift penalties, effectively meaning this is reduced to
  XX for 1 year.
- My husband can never return to shift work as he is required to maintain his sleep patterns to prevent future relapse. This essentially reduces his annual income by a further \$25,000.
- The cost of his multiple medications is about \$200 per month and will continue at that level for 1 year since his initial episode, with the potential for some ongoing medication costs. 1
- His GP visits have totalled ~\$500 out of pocket.
- His Psychologist is in part subsidised by Medicare although has so far had an out of pocket cost of ~\$500.
- The psychiatrist cost is \$150 per session out of pocket, and over the course of this first year, will probably exceed \$800 out of pocket.
- Bipolar includes symptoms of irrational and impulsive spending. Before the diagnosis when it
  was unclear what was happening, the cost of his impulsive spending totalled about \$500 and
  could easily have been more if not closely monitored.

<sup>&</sup>lt;sup>1</sup> He does have private health insurance, however, unless you have the top level of cover, mental illness does not appear to be covered to any degree.

It is not hard to see how if a person is not supported by a stable family and home life, that other issues such as homelessness, loss of job etc would so easily flow from such an experience.

The cost alone is a burden, however, it also adds financial and emotional stress that an illness which was not my husbands fault or caused by any wrong doing on his part, can suddenly have such an impact on our lives.

## To outline the social cost of our experience:

- Prior to my husbands psychotic episodes and diagnosis we would on average eat out 2 or 3
  nights a week and regularly spend time with friends at bars and cafes etc. I would summarise
  it as an active social city lifestyle. However, the impact of recovering from severe mania,
  coupled with the side effects of the medication which makes him feel introverted and
  continually restless, we have scaled back our social commitments significantly.
- For the first 3 months after the initial episode we socialised only with immediate family and mostly in the home.
- Now, still bound by the side effects of medication we socialise occasionally and are also conscious of spending less money given the reduced income and other costs as outlined above.
- My husbands gym membership also went unused for a period of about 6 weeks as he recovered initially, which, while necessary also doesn't help promote good mental health.
- His job required him to change to a different division given he cannot work shift work hours.
   This is the only position made available to him and is one which is repetitive and mundane in nature, compared to his previous role which was highly varied. This has a social cost towards his overall mental state in recovering to be able to return to work full time in a role which is not the job he previously held and does not interest him.

## Suggested areas for change:

- Workplace First Aid for Mental Illness: The government is in a position to legislate that a
  specific number of workers in each organisation hold a current first aid certificate and this
  should also include First Aid for Mental Illness. I understand this may not be possible for
  small size organisations, however, the overall understanding, awareness and perception of
  mental illness would drastically improve. This would also strongly support employees who
  have a Mental Illness by knowing people in their place of employment have undertaken such
  training.
- Informal carers: One of the biggest barriers I have faced as the primary informal carer, is the notion of patient confidentiality and that my husband would tell various health care workers "he felt fine" and "everything is ok" (except he was mid psychosis and wasn't ok but didn't know it). I was sent away from an emergency department in Sydney while my husband was in the initial stage of his psychosis and told to just take him home and sleep because he told the Doctor he felt fine. The community health team called once and again he responded everything was find and hung up the phone no one thought to call me and ask if I as a person not in psychosis thought he was ok. It was only when he physically couldn't walk and I took him to the community mental health office was I taken seriously that he was not ok. This barrier of confidentiality is also met through making medical appointments and changing them, which is a key role of the informal carer. I'd imagine if you didn't have shared bank accounts etc it would also be met in that scenario.
- **Professional health care workers**: A number of health care workers over the past few months have been fantastic, however, there is definitely a gap when you present at a GP office and/or emergency department appearing physically fine, and ask for assistance from a

- psychiatrist. My husband was initially told by his GP he did not need to see a psychiatrist, and we were also sent away from an emergency department and told he just needed a good night sleep. On both occasions he was exhibiting key signs of mania e.g. talking excessively, elevated mood, unable to sleep, unable to maintain a chain of thought. I am not privy to the level of general mental health care training in the medical profession, however, it would appear the notion of "well you look fine" still exists.
- Income support: I note the Commissions commentary on income support. I do not believe the current Centrelink system is set up to support those with mental illness which is impeding their ability to work. There is enough paperwork, appointments, medications to remember, that I would be surprised if applying for and receiving the Disability Support Pension is without further stress to an already stressful scenario. Furthermore, the Centrelink payment is means tested for reasons which I understand, however, mental illness does not only happen to those which would qualify for Centrelink support. My counter suggestion to the Commission would be to recommend that all medication and medical appointments which relate to mental health be funded by the government so that while not everyone may qualify for DSP, everyone with a mental illness is not financially disadvantaged by the cost of getting healthy again.

The shear notion of the Productivity Commission doing a report on improving Mental Health is a credit to how far mental illness has come in Australia, however, there appears to still be significant areas of improvement. I hope that the above detailed account of the economic and social costs of psychosis and furthermore a diagnosis of Bipolar on a young working male professional help highlight that mental illness does not discriminate and that the support functions need to cover everyone in our society.