

We are the parents of a son with a severe mental illness. We have outlined the things that of greatest concern to us relating to carers allowance, employment, respite and future care.

We are fifty three and sixty years of age, with a son who is aged twenty four years and has schizophrenia.

He has not responded well to current available treatments and has spent four years in hospital. He is now discharged from hospital and under our care. At this time he is unable to work and no-one can predict what the future holds for him.

His current level of medication keeps him so sedated that he is now unable to drive a motor vehicle and constantly needs a lot of rest.

It is mandatory that his medication be taken daily and we are never be able to have even **one day** away from him due to this need to supervise his medication.

When he was discharged from his long hospitalisation I (his mother) resigned from my employment and had three months with him to help with his integration back into society. There is no possibility of replacing my lost income as my husband is employed (although last week he suffered from a heart attack so I just hope he lives long enough to keep us all going).

When applying for the carer allowance it became obvious that the forms used are all geared towards those with physical disabilities and not mental health issue, making it very difficult to have the role we play and the effect of my loss of income recognised.

Many families these days **need** two incomes to survive financially, and the loss of one of those, due to the caring role, will I am sure, never be recognised.

We have considered moving away from Sydney, to an area where it is cheaper to live, but feel this is not an option for us due to the severity of our son's illness and the need to be close to mental health facilities.

Both country and coastal areas outside Sydney, have a reputation of lacking mental health facilities, and we just can't predict what will happen. We also feel that we would be excluded from any "over fifty five developments" or retirement village because of our caring role due to the age and the discriminatory nature of our son's illness.

In order for me to resume employment I have taken a part time, lower paid job with less responsibility, so that I can be available, if needed, to assist my son.

I feel quite fortunate to have this opportunity as at my age a change of career for most people would be nearly impossible, and, at least I have a job.

Whilst my husband was having his angiogram I had plenty of time to contemplate how I would possibly manage without his financial support and could I really care for my son without his emotional support and it really was a very frightening experience to which I have no solution.

There are times when we will all need urgent respite from our caring role and it would be good to know that it would be available when needed. We also need regular planned respite.

When assistance is given to provide meaningful activity, friendship, community participation and employment training and opportunity for those with a mental illness then my role as a carer is supported. My son has been able to attend one of the new

“day to day living centres” and this has been enormously helpful. The need for more of these centres cannot be emphasised enough.

However, **these need to be placed more locally, we live in one of the fastest growing regions of Sydney (the North West Sector). There are three centres in the Parramatta CBD, all run by separate organisations and funding, yet nothing in the Hills. So we feel that the co-ordination of the placement of these centres needs better planning.**

When a disability causes you to lose your ability to drive it means that many hours per day are lost in travel on the minimal public transport available. We are also planning to access the new mentoring program but have not done so yet, a more convenient location would assist with this.

As carers before we can confidently access employment or make other lifestyle choices we need to know that our mental health facilities have the capacity to manage the needs of the mentally ill. That a bed **will** be available when acute admission is required and that community services **will** be available to provide back up support and that we may even have a choice of where we should live, knowing that adequate facilities are available for everyone.

One of our major unanswered questions at the moment is what would happen to our son when we die or become too incapacitated to care for him?

It would be comforting to know that such urgent matters are on the minds of our politicians and that forms of affordable supported accommodation are being planned, because these need to be long term well designed projects that will take time and effort to get right.

Many surveys and assessments of carers needs have already been done in the past. What really needs to be done is the follow up action required to implement the recommendations.