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Submission No. 1118

(Inq into better support for carers)

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Secretary  
Inquiry into Better Support for Carers  
Standing committee on Family, Community, Housing and Youth  
PO Box 6021  
House of Representatives  
Parliament House  
Canberra ACT 2600

Dear Secretary,

I wish to make a submission to the House of Representatives Standing Committee on Family, community, Housing and Youth's Inquiry into Better support for Carers.

Our third son has had ongoing mental health problems since he was 16. He is now 37. When he was first diagnosed I still had two younger children, and had just thought I might return to the work force. I quickly had to give up that idea, as we never knew when I would be needed at home or at the hospital.

In the early years of this disease, life was very unstable He was prone to erupt at the slightest provocation, and attempted suicide 3 times. This is very wearing on the health and the dynamics of the rest of the family. It affects the study environment of siblings, and the relations between husband and wife.

Sometimes we have had help from the hospital system, and sometimes they have been worse than useless. The biggest problems have been caused by

1. Lack of supervision at the hospitals, allowing him to go walk about.. Eg from Wacol in 2000 to jump off a bridge, and smash his heels, ankles, and break one leg.. He wasn't found for 28 hours by which time his feet were so infected, he nearly had one amputated.
2. Being discharged too early, followed by more trauma before readmission.

Andrew lives with us when he is not in hospital. He has just been discharged from an extended stay in hospitals. He smokes continuously and we do not, and the house smells.

We are now at the point where my husband has retired, and we would like to have out home to ourselves, and to be able to move around, before we are too old to be able to do so, but there is nowhere else for him to live. He needs to be somewhere, with support to make sure he changes his clothes, takes medication, keeps doctors appointments has blood tests etc etc.

Sooner or later we are going to be unable to look after him, and still there will be nowhere for him to live.

I have just been informed by the Disability Services Dept. that since he is not in danger of going into an aged care facility ( because we are still caring for him) that they cannot help us.

General points.

1. The carer's allowance assessment form does not ask the right questions. They assume we are talking about a physical disability. Mental disabilities are quite different.

Don't ask "can he shower himself" ask "does he shower himself, without being hounded" NO

Don't ask "can he feed himself" ask "can he cook for himself" NO

Don't ask "can he clean his teeth" ask "does he clean his teeth" NO

Do you get the idea?

Then access to other services can be dependant on receiving that carer's allowance. This is unfair.

2. When the medication is working and being taken as required they can appear to be fairly normal. Some may even hold down a regular job, but as soon as something goes wrong it is our responsibility to make sure they get treatment. This can be easy, but more often is a nightmare. We had to call the police to have him readmitted a number of times.
3. Getting treatment in the first place can be very difficult these days. I have heard too many stories of persons being taken to hospital asking for help, and being turned away. I suppose this is due to lack of beds, but the parents are left devastated. If you had any idea how hard it is to get a psychotic adult child to the hospital in the first place, you might understand what that does to the parents.
4. Again in this first place, the parents are usually completely unprepared for what is happening. It is a very frightening world to enter for the first time, and it takes many years to learn the jargon, and where to go for what, and then the rules keep changing anyway.
5. A further source of angst for parents is being told by the doctor that they cannot be involved in the treatment of their adult child. Some doctors even refuse to accept information from parents re the patient's behaviour. The parents are the ones who have to live with it, they know what is happening, and they deserve to be considered.
6. One of the possible symptoms of some mental health illnesses is an irresponsibility with money. They waste their money, or get into debt. They go interstate or even overseas, and then require rescuing. This saps the resources of the parents. Some I have met are almost broke, supporting them. This becomes worse when the son brings home a wife and child, but cannot manage his money well enough to care for them.
7. If your mentally ill relative happens to have another problem, eg drugs or alcohol, there are few places equipped to deal with them.
8. What we need most is somewhere for him to live away from us, but close enough to use public transport to visit, with support to make sure he continues to take his medication etc etc.

I hope this will go some way to helping you understand what a precarious life we lead.

Pat