

Submission No. 978

(Inq into better support for carers)

4th July, 2008

To the secretary of the committee

TO WHOM IT MAY CONCERN

I'm not sure if I am writing this properly but here goes. I have been a carer for my husband for the last two and half years. Up until 2006 he had suffered 6 psychotic episodes over 28 years and diagnosed as schizophrenia or manic depression. He would be hospitalized for approx 2 -4 weeks, then home for a short while on medication and then back to his employment. We had no help from any sort of service or told where we could get advice and help. We had to do it ourselves (me) alone. To bring you forward to now, well actually January 2006, my husband another psychotic episode and hospitalized once again for about 6 weeks. This episode was completely different to the others in terms of some of his symptoms. He was in a private hospital for a week and then transferred to a public hospital where he was put into the locked (secure) area as the doctors were afraid that he may harm himself or others. After two weeks he was then transferred back to the private hospital. This episode was different in that he did not bounce back to his normal self and back to employment. He is now on a disability pension and I a carers pension. With all this going on myself and my 3 sons had no help or information as to what was available to us in terms of counseling for me and especially my 3 sons. They were younger when my husband had his previous episodes (I had kept them away from their dad as I didn't want them to see him in that state) and they could not understand what was going on. I went to Centrelink to see what was available and I had to ask (that was if I knew what to ask for as information was never volunteered by them) and argue and argue with them for help. I left there in tears many times as they made it so hard just to get a little help that I felt we were entitled to. This (with Centrelink) went on for about 16 months before we got the disability and carer pensions. Also centrelink should straight away have a Case Worker instead of waiting in queues to see just anybody that you have to explain everything all over again.

My main point is LACK OF INFORMATION given to the patient or carer from the hospital, psychiatrists, doctors or anyone else as to where you can get help and support. Support groups for the patient are hard to find unless you spend hours on the internet and then they are usually in the city which makes it hard to get to. Support for carers is even harder to find. From spending many hours on the internet (and who is paying for all this time on the internet or phone – me, the carer) to find support for me, I was put in touch with the Carer Respite Centre in Dandenong and have been having one to one visits for myself and gained information from this person to help me cope emotionally and financially and also time out. I have only just got into a support group now and find it very helpful to know that there are others going through the same or similar to me. I also found out recently, from the Carers in Victoria magazine, that there is counseling available for the carer. I have had to do this through my GP and medicare.

All that I have written should be made available to patient/carer without all the hassle that I have had to go through, which made me feel as if we were not entitled to anything, which was very wrong.

Lack of information for help

Lack of support for patient and carer (eg groups, one on one)

Lack of financial support

Lack of legal support (Power of attorney etc)

Annette

Carer for my husband John.