

AOC 10/7/08

Submission No. 691  
(Inq into better support for carers)



beyondblue  
the national depression initiative  
www.beyondblue.org.au

4 July 2008

Committee Secretary  
Standing Committee on Family, Community, Housing and Youth  
PO Box 6021  
House of Representatives  
Parliament House  
CANBERRA ACT 2600

Re: National Health and Hospital Reforms Commission  
Inquiry into better support for carers

Summary and Recommendations:

Caring for a person with a mental health problem, such as depression, anxiety or bipolar disorder, has a significant impact on carers and family members. The carer role is compounded by the ongoing and often unrelenting daily challenges associated with caring for a person with depression and related disorders together with the current lack of support and understanding of mental health from the wider community.

The carer's role is often further impeded by issues of confidentiality which, under the current legislation, can prevent carers from being informed and involved in the treatment of their family member. The resulting burden of care, absence of information, support and respite for carers ultimately has a significant impact on the psychological, physical and emotional wellbeing of carers.

In response to these issues, *beyondblue*; the national depression initiative and blueVoices, the consumer and carer arm of *beyondblue*, recommends that there is greater acknowledgement and inclusion of carers within the treatment process. This includes greater information provision to carers and, in particular, a review of the current legislation surrounding issues of privacy and confidentiality. We also recommend the expansion of respite services with greater consideration given to those caring for people with high prevalence, non-psychotic illnesses.

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## Background

*beyondblue* is a national, independent, not-for-profit organisation working to address issues associated with depression, anxiety and related substance misuse disorders in Australia. One of *beyondblue*'s priority areas is to provide people living with depression and related disorders (anxiety, related substance misuse, bipolar disorder) and their carers with information on these illnesses and effective treatment options, and promoting their needs and experiences with policy makers and healthcare service providers. At *beyondblue*, carers are defined as those people directly affected by or having a significant role in the life of a person with depression or related disorders.

Depression is the most debilitating illness in Australia<sup>1</sup>. Research indicates that whilst caring for a person with a physical or mental health condition places carers at significant risk of depression<sup>2</sup> for those caring for a person with a mental illness, this risk is exacerbated by issues of stigma and the lack of community understanding of mental illness<sup>3</sup>. Caring for a person with one of these disorders also presents unique challenges when considering the non-overt, cyclical and episodic nature of these disorders which leads carers to describe their caring role as unrelenting, intense, isolating and exhausting<sup>4-5</sup>. This highlights the need for respite options for these carers which are currently limited.

*beyondblue*'s national reference group blueVoices, includes people with direct or indirect experience of depression, anxiety, perinatal depression or anxiety, bipolar disorder, co-morbid substance misuse or co-morbid chronic physical illness. blueVoices is the co-ordinated voice of consumers and carers and serves to provide *beyondblue* with consumer and carer perspectives.

blueVoices has highlighted the issue of limited access to information about the person they are caring for and their role in the decision-making process. This issue has been consistently echoed in *beyondblue* carer research<sup>3-5</sup> and most recently reinforced in a specific on-line feedback forum with blueVoices members (May, 2008).

In particular, privacy and confidentiality guidelines are stressors for carers who are not included in the decision making process nor consulted about symptoms, treatment compliance or at-risk behaviour. This is exemplified in some of the statements derived from the recent on-line survey of blueVoices members.

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<sup>1</sup> Mathers C, Vos T & Stevenson C (1999) *The burden of disease and injury in Australia*, AIHW Cat No PHE-17, Australian Institute of Health and Welfare, Canberra.

<sup>2</sup> Cummins RA & Hughes J (2007) *The wellbeing of Australians – Carer Health and Wellbeing*. Australian Unity Wellbeing Index. Survey 17.1.

<sup>3</sup> Hight, N.J. McNair, B, Davenport TA & Hickie, IB (2004) – How much more can we lose?: Carer perspectives on living with a person with depression. *Medical Journal of Australia*. Vol 181 No 7

<sup>4</sup> Hight NJ, Thompson, M & McNair B. Living with Depression – the carers experience. *beyondblue* Research Update.

<sup>5</sup> Hight NJ & Thompson M (2002) The impact of living with anxiety – carer's perspectives. *beyondblue* Research Update.

*I knew something wasn't right – but he wouldn't tell me – they never told us he tried to commit suicide in hospital yet he was released in my care.*

*I felt that he was going to the sessions and he'd be doing things that I couldn't follow up because I didn't know what they were doing with him, and I felt like I was really left out.*

*When you say 'what do we want?' consult the carer. I know there are privacy problems and that sort of thing, well just too bad. You're going to have to sort it out because the professionals are running on a tenth of the information they should have.*

*There wasn't communication and I'd write letters and say; 'I don't want to impinge on any private stuff, I just need some help in management'.... And there was just nothing back at all. In the end I'd write letters saying 'please can we work in some sort of partnership'... there's a difference between being a nosy parent and being a caring parent.*

*I think you need to educate the doctors, the GPs, and the mental health services to actually make more information available for parents and carers, because they don't. You have to search for it yourself.*

*The positive experiences we have had have been mainly through the private health system – the consultant would discuss his condition with us – he would accept phone calls from us when he was very ill and either hospitalised or when we were particularly concerned about his condition*

*In summary, beyondblue recommends that the Commission pay specific attention to the outlined issues of confidentiality and respite options for carers of people with high prevalence disorders.*

Yours faithfully,



Leonie Young  
Chief Executive Officer  
beyondblue: the national depression initiative



Rev Lyn Chaplin  
Chair  
blueVoices