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Submission No. 842

(Inq into better support for carers)

Carolyn

Inquiry into Better Support for Carers

Dear Secretary

I wish to add my experience and opinion to help better understand and support carers.

I care for my adult daughter who has a range of mental and emotional health issues. I have supported her solely for the past 5 years.

My role as carer is 24 hour availability, at times to simply hold her hand so she knows she's not alone and someone loves her. She doesn't require a lot of physical assistance however she needs constant re-assurance that I'm here and she's going to be OK.

My daughter's illness is very complex and I am still going through the process of understanding it, to this very day, just as she is still unravelling things for herself. As she has a range of issues and symptoms her diagnosis doesn't fit neatly into a box, therefore there's no "one size fits all" answer.

I consider myself a strong and intelligent woman however the role and responsibility of carer has brought me to my knees at times.

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My caring role effects my life with feelings of being overwhelmed, frustrated, resentful, alone and angry. Constant worry about my daughters behaviour and lack of function, fear about the future and our financial security. This has caused me severe depression to the point where I have been unable to function. The I felt guilty, hopeless and ashamed of myself for not being stronger.

I would have to say the stigma attached to mental illness probably has the most profound effect for both myself and my daughter.

Physical disability immediately gets a sympathetic response and does not need explanation, whereas mental illness is judged as being weak and simply about bad behaviour. This attitude effects the carer as much as it effects the cared for. Family and friends have no comprehension of the reality of living with mental illness. From my experience some professionals (perhaps many) are the same.

This has made it very difficult and sometimes nearly impossible to reach out for help because in doing so we have to prove there really is a problem. That has caused me (and my daughter) to feel as though we are not believed.

My other major concern is not being heard. I have felt alienated by my daughters treating psychiatrist (approx 4 years) who at no time has spoken to me so that I can gain a better understanding of the best way to help and support my daughter. I believe very strongly that family members need to be included in some way. Also that they have some insight to offer.

As I have been given no direction my biggest fear is that I could help or harm my daughters progress.

My daughter and I have both lost our own homes and now find ourselves struggling financially. An added burden.

Each disabled person and each carer requires individual consideration as we all respond differently to our life circumstances. This does not reflect on us as individuals because our personality and life experience combines to make us who we are. And that makes each of us a one off. Therefore we can't be grouped together under one heading and one set of guidelines.

As a carer we support individuals who otherwise would require government intervention and responsibility because Australia is not a 3rd world country and is built on human compassion which is a basic right in this country.

Thankyou for listening,

Carolyn