

RESEARCH UPDATE



Living with Depression: The Carer's Experience



This research project was conducted by *beyondblue: the national depression initiative* and has been integrated with the research of The Network for Carers of People with a Mental Illness.

The research explores the experiences of carers of people with depression and reveals how living with a person with depression can impact on many areas of life and affect psychological, emotional and physical well-being. It also indicates how the carer's experience of accessing effective treatment for the person with the disorder may compound the burden of care.

Based on the experiences of the people involved in this research project, the needs of such families appear largely unrecognised by health professionals, services, and the wider community. Drawing on carers' views and experiences, this research offers a way forward.

The full report from which this research summary is drawn is available to download from the contributing organisations' websites.

The research was conducted by

Nicole J Highet, DPsych
Senior Researcher, *beyondblue: the national depression initiative*

Marie Thompson, BSc (Hons)
Research and Program Officer, *beyondblue: the national depression initiative*

and

Bernard McNair, Grad Dip Nursing Mgt
'blueVoices' National Coalition Coordinator,
beyondblue: the national depression initiative

Integrated with the research of The Network for Carers of People with a Mental Illness (represented by John McGrath, Chair of The Network, Anxiety Recovery Centre Victoria, Carers Victoria, and the Eating Disorders Foundation of Victoria)

This research was funded by *beyondblue: the national depression initiative*

beyondblue: the national depression initiative

beyondblue is an independent, national, not-for-profit organisation working to remove the stigma of depression and related disorders in Australia and to raise awareness of these disorders as a serious national health problem. In addition to raising community awareness, *beyondblue* addresses consumer and carer issues and conducts research.

Project Partnership

This research update provides a summary of Part Three of a larger ongoing project and specifically addresses the experiences and needs of carers of people with depression. The larger project is in collaboration with The Network for Carers of People with a Mental Illness and also investigates and compares carers' needs and experiences in relation to eating disorders and anxiety disorders.

The Network is the peak carer body in Victoria in the mental health community and its membership includes organisations and groups that provide day-to-day support to carers and their families.

Depression

Over a million people in Australia live with depression each year. One in five people experience depression at some point in their adult lifetime.

Depression is not simply a low mood but is a debilitating illness. People with depression find it hard to function every day. Depression has serious effects on physical as well as mental health.

Research Objectives

The research had four aims:

- To explore the experience of living with and caring for a person with depression
- To understand the impact of this experience on primary carers and the family
- To identify factors contributing to the burden of care
- To highlight opportunities to improve the lives of those living with a family member with depression.

Methodology

Six focus groups (each consisting of two sessions) were conducted with primary carers of people with depression across Australia in 2001 and 2002. Between six and eight people were initially recruited to attend the focus groups (each of two-hour duration).

As most of the focus groups were conducted within metropolitan regions of Australia, in-depth telephone interviews were conducted with carers living in rural and remote localities.

Research Findings

On analysing the results a number of consistent themes emerged and are summarised below. Caring for a person with depression has a profound impact upon the carer and families across the various stages of illness.

1. Barriers to identifying depression

Carers describe behavioural, physical and psychological signs as early indicators of the presence of depression in a family member, yet mostly these signs are only understood in hindsight. A number of barriers prevent carers from recognising the development of the disorder at the time. These include the gradual onset of the illness and a lack of general knowledge of the illness, causing carers to dismiss potential indicators and misattribute signs and symptoms to a transient phase or personality trait.

"It actually crept up on both of us ... when you're actually there you don't necessarily see the emergence."

"You think it's because they're going through their teens."

2. Recognition of depression

Carers report a complex emotional response follows the realisation that a family member has depression. Carers commonly experience denial, shock, fear, confusion, guilt, blame and grief.

"So for the two of us it's really been feelings of guilt. What has been our genetic predisposition that we have bequeathed to our children? That's how we've felt ... it zeros in on your guilt. Every time. Like a bulls eye. Bang."

"The sadness ... that your off spring will not reach their full potential."

3. The overwhelming burden on the carer

A number of distinct aspects to the role were reported to contribute to the strain associated with caring for a person with depression. The elements which carers describe as leading to increased burden relate to the overwhelming, unrelenting nature of the role and to the high levels of responsibility associated with it.

"The implications for me? It's just completely changed my whole life."

"I don't think I was actually ever asleep for months and months on end."

"You have to be ever vigilant. ... It's like, you know, when a dog goes to sleep it's always got one ear up? That's what it's like caring for someone with depression."

4. Impact on relationships

Family, spousal and social relationships are affected by the presence of depression. Family routine and activities are disrupted and dynamics within relationships alter and are constantly changing.

"That constant pull on the whole family ... and it causes major family disturbances."

"I have to try and step back and say, 'I am no longer your carer, I am now husband again.'"

"Our social world really stopped at one stage. We didn't do anything. We didn't go out. ... We felt guilty if we went out and left him."

5. Financial impact

Caring for a person with depression can have a significant financial impact, not only with respect to accessing treatments but also in instances where the person is unable to work. The carer may also have little choice but to give up their job in order to care for their family member.

"He hasn't worked since last August. I've had to re-finance our home."

"I had to give up work to care for my husband. So it got to the point that there was nothing else in my life other than caring for my husband and his depression."

6. The impact of self-harm and suicidal thoughts and behaviour

The potential threat of self-harm means carers have to remain vigilant, often living in fear of what their family member might do. Such thoughts and feelings are described as being highly disruptive, disturbing and exhausting.

"I've found it really hard because our daughter has been suicidal ... sometimes you just want to relax and be a bit more low key, but you can't because it might happen again."

"We have threatened suicides several times. He never did try, but the threat is as bad as the trying in a way because you are on tenterhooks the whole time."

7. Barriers to accessing treatment

Carers identified a number of barriers in accessing treatment for a family member. These include lack of information, delay in obtaining a diagnosis, the protracted process of accessing intervention and proximity to services.

"I had no experience, no background. I didn't know who to turn to. You don't want to tell your friends so I really didn't know who to turn to."

"It was a long chain of events to try and get him to a psychiatrist to get some medication. It's been a long journey."

"The only health professionals we have here [in the country] is a nurse and a GP. There are people [professionals] in the city - we want it here."

Carers are often left to deal with their family member, leading many to feel overwhelmed and out of their depth.

"And in the meantime I have to deal with the problem. And I'm a layperson - I just don't know how!"

The impact of this is exacerbated when carers are excluded from the treatment process, leaving them uninformed and unsupported. In some instances this leads carers to believe that health professionals blame them for the development or progression of the disorder.

"We are part of a team and I don't care if I am the problem. I would rather they told me 'look you're doing this wrong', it would be better. But don't ignore me. I'm the one she comes home to."

"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 about a tenth of the information they should have."

"It's almost as if it's our fault. It's almost as if they make a deliberate thing of not wanting us to be involved."

The burden for carers is intensified by inappropriate detection, treatment and management of depression by health professionals. In turn, this results in an ongoing, untreated illness which continues to have significant impact on the carers and families.

"Even the GP was like, 'it's only depression, it's not anything major.'"

"GPs should have the humility to recognise and refer rather than trying treatments ... it really does take an expert to get it right."

8. Stigma and lack of awareness about depression

Carer burden is often further exacerbated by the stigma and lack of awareness and understanding about depression in the community. Ultimately this reduces the capacity for carers to get support and empathy from family and friends, increasing their isolation and compounding the impact of the illness (placing the carer at greater risk of experiencing depression themselves).

"I don't know whether it was because they were actually genetically related and maybe they thought they were going to catch it or something. But they [family members] ... would back off and you wouldn't hear from them. And it hurt. I was really hurt."

"It's been so beneficial to me being involved in a carers group... just hearing everybody's story, and hang on, I'm not the only one going through this."

Conclusions

- Depression has a profound impact upon the carer and family – from the early signs of development and the detection process through to the more severe stages of the disorder.
- The numerous barriers to accessing effective intervention for a family member can exacerbate the strain associated with caring for a person with depression.
- The experiences and needs of carers and families appear largely unrecognised or ignored by health professionals, services and the wider community.

Recommendations

- Increase community awareness about signs and symptoms of depression. This could improve detection and early intervention, reduce isolation, increase the level of support for carers and alleviate their burden of care.

- Increase community awareness and understanding about the significant impact depression has on those who live with them. This will assist in reducing the stigma for the person with the disorder and their family, and may increase the level of empathy and support provided to carers.
- Recognise the needs of carers and provide support when they are dealing with the implications of depression and the profound impact the condition can have on the individual and family.
- Review health policy pertaining to depression management practices and carers' needs.
- Ensure that support services and networks for carers in metropolitan and rural areas can be adequately funded, available and accessible.
- Encourage health professionals to share information with carers about the disorder and its management, information about appropriate services, and eligibility for assistance including mutual support groups and financial entitlements.
- Encourage health professionals to better understand and respond to carers' needs and concerns, and to promote a more inclusive approach to treatment and management.

Based on the outcomes of this research, *beyondblue*, The Network of Carers of People with a Mental Illness and the other relevant organisations will respond to the recommendations in line with their strategic directions and forward planning.

For more information or to view a full report online

beyondblue: the national depression initiative

Telephone: 03 9810 6100 nicole.highet@beyondblue.org.au
To view the full report online: www.beyondblue.org.au

The Network of Carers of People with a Mental Illness

Telephone: 03 9889 3733 info@carersnetwork.org
To view the full report online: www.carersnetwork.org

Anxiety Recovery Centre Victoria

Telephone: 03 9886 9377 arcmail@arcvic.com.au
To view the full report online: www.arcvic.com.au

Eating Disorders Foundation of Victoria

Telephone: 03 9885 0318 or non-metro: 1300 550 236
edfv@eatingdisorders.org.au
To view the full report online: www.eatingdisorders.org.au

Carers Association of Victoria

Telephone: 03 9396 9500 Freecall: 1800 242 636
cav@carersvic.org.au
To view the full report online: www.carersvic.org.au

© *beyondblue: the national depression initiative* and The Network for Carers of People with a Mental Illness. Melbourne, Australia 2004

