

# RESEARCH UPDATE



## Living with an Anxiety Disorder: The Carer's Experience



Conducted by *beyondblue: the national depression initiative* and The Network for Carers of People with a Mental Illness, this research summary explores the experiences of carers of people with an anxiety disorder.

This qualitative research reveals how living with a person with an anxiety disorder, such as obsessive compulsive disorder, generalised anxiety disorder, social anxiety disorder and panic disorder can impact on many areas of life for the carer and families and affect their psychological, emotional and physical well-being.

The research also reveals how difficulties in accessing effective treatment for the person with the disorder may compound the burden of care.

The needs of the carers and families who took part in this research project appear largely unrecognised by health professionals, services and the wider community. Drawing on their 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*  
and  
Marie Thompson (BSc Hons)  
Research and Program Officer  
*beyondblue:*  
*the national depression initiative*

### In partnership with the Project Management Team:

Chair: John McGrath, The Network for Carers of People with a Mental Illness.  
**Co-investigators:**  
Karen Elford, Executive Officer,  
The Eating Disorders Foundation of Victoria  
Kathryn l'Anson, Director,  
Anxiety Recovery Centre Victoria  
Kim Johnson, Carer Representative  
Julie Nankervis, Policy Officer, Carers Victoria

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

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

*beyondblue: the national depression initiative*  
PO Box 6100  
HAWTHORN WEST VIC 3122  
Telephone: +61 3 9810 6100  
Fax: +61 3 9810 6111  
Email: [bb@beyondblue.org.au](mailto:bb@beyondblue.org.au)  
Website: [www.beyondblue.org.au](http://www.beyondblue.org.au)

Anxiety Recovery Centre Victoria  
42 High Street Road Ashwood VIC 3147  
PO Box 358 Mt Waverley VIC 3149  
Telephone: +61 3 9886 9377  
Fax: +61 3 9886 9411  
Email: [arcmail@arcvic.com.au](mailto:arcmail@arcvic.com.au)  
Website: [www.arcvic.com.au](http://www.arcvic.com.au)

## ***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.

## **The Network for Carers of People with a Mental Illness**

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. The Network also has family carers as active members who bring practical experience to its decision-making process.

## **Project Partnership**

This research update provides a summary of Part Two of a larger ongoing project and specifically addresses the experiences and needs of carers of people with anxiety disorders. The larger project is also investigating carers' needs and experiences in relation to eating disorders and depression.

## **Anxiety Disorders**

Anxiety disorders are the most common mental disorders affecting people in Australia. Estimates of the lifetime prevalence of anxiety disorders range between 13% and 26% of the population. This study focused specifically upon obsessive compulsive disorder, generalised anxiety disorder, social anxiety disorder and panic disorder. The onset of anxiety disorders is generally in late childhood or adolescence. The female to male ratio of anxiety disorders is 2:1 for panic disorder and social anxiety disorder; 2.5:1 in generalised anxiety disorder; and 1:1 in obsessive compulsive disorder (OCD).

## **Research Objectives**

The research had four aims:

- To explore the experience of living with and caring for a person with obsessive compulsive disorder, generalised anxiety disorder, social anxiety disorder and panic disorder
- 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 people living with a family member with an anxiety disorder.

## **Methodology**

Six focus groups (three groups each consisting of two sessions) and seven in-depth interviews were conducted with the primary carers of people with an anxiety disorder in both rural and metropolitan Victoria in 2003.

## **Research Findings**

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

### **1. Barriers to identifying an anxiety disorder**

Carers describe behavioural, physical or psychological signs as early indicators of the presence of an anxiety disorder in a family member, yet mostly these signs are only recognised in hindsight. A number of barriers prevent carers from noticing the development of the disorder at the time. These include family members hiding their symptoms due to feelings of shame and fear, carers' lack of awareness of anxiety disorder symptoms or incorrectly attributing the symptoms to a phase of adolescence, naughtiness, eccentricity or personality traits.

*"Initially I thought she was different. We didn't know that a lot of things were classic signs of OCD."*

### **2. Recognition of an anxiety disorder**

Carers report a complex psychological response to the realisation that a family member has an anxiety disorder. Guilt, fear, sadness, grief, loss, shock and anger are common.

*"I felt pretty terrible because I hadn't recognised it."*

*"I was worried about his life mainly, and then mine. How would I cope during the time he needed me most?"*

### **3. Family involvement in symptoms**

In an attempt to alleviate the distress experienced by the person with an anxiety disorder, family members frequently engage in and accommodate symptoms of the disorder. As a result, carers report that the symptoms of OCD become intrinsically intertwined into all aspects of living.

*"You're part of their illness. It's your illness too, in a way."*

*"With germs, I was afraid to sneeze. I'm not allowed to pick up the telephone without washing my hands, if I open doors, I have to use my foot. I have to climb over the fence to get into my own house."*

Accommodating and living with the symptoms of OCD impacts upon the quality of life of all family members involved. The symptoms appear to control, dominate and infiltrate into most, if not all, areas of life.

*“Abnormal becomes normal ... You adjust to the other person, mould yourself.”*

*“You’re on edge or there’s a volcano ready to erupt ... there’s always this big uneasiness or tension.”*

Carers of people with panic or generalised anxiety disorder feel constrained by the dependency of their family member. Their family member’s need for the carer to be in close proximity, to provide constant reassurance and undertake daily activities for them, leaves many carers feeling trapped by their role.

*“I can’t be with him 24 hours a day, and if something’s happened and I’m delayed, he will panic, he will massively panic over my delay. ... It makes me feel a bit closed in.”*

*“I’m constantly running around to take her here and there.”*

#### **4. Impact on relationships**

Caring for a person with an anxiety disorder can be particularly demanding and places considerable strain on spousal, family and social relationships. Over time, the impact of living with the symptoms can become a burden and hinders the progression of secure and balanced relationships. Intimacy and dynamics within the relationship are also altered.

*“I also have some grief in the sense that I missed out on a normal marriage. I’m more his mother than his wife. I’m the carer. There’s affection, but there’s no physical side to our marriage, it finished about three months after we got married.”*

*“It affects the whole family, because we’ve basically got to be on tenterhooks with him all the time.”*

*“I’m an extrovert, I love people – and he was reluctant to go out with other people. He didn’t want to have other people in our home and to go out. And that became a burden.”*

#### **5. Financial impact**

Living with a family member with an anxiety disorder often impacts financially on the carer. Anxiety disorders sometimes debilitate the person to the extent that they are unable to work.

*“I’ve been backing my daughter financially because she can’t work ... and (I’ve been) paying whatever to get her by. She does budget but I have to help her get by on a very regular basis.”*

Certain symptoms have a direct influence on family finances. For example in the case of OCD, throwing away food or clothes due to fears of contamination is common. Over time, this disposal of “contaminated” items becomes costly, and impacts upon the financial status of the family.

*“And the waste of food, if he thinks it’s been touched and opened he won’t have it. Clothes I buy for him, sometimes they might just end up on the pile on the floor.”*

#### **6. Impact on psychological, emotional and physical wellbeing of carers**

Carers report becoming so intertwined with the disorder that their own needs and a life outside of their caring role becomes difficult for them to consider and many describe feeling trapped and defined by their role. Carers are overwhelmed by the unrelenting nature of the role and experience chronic stress, symptoms of depression and related physical complaints.

*“Maybe this is my career or something.”*

*“The weight is on you and you do suffer from it (depression). You sort of wilt and get cranky... the demands that are put on you, you do get that way.”*

*“On a physical level, how it affects you physically, how you feel, how your body feels, health-wise and that. ... My body can actually feel it. I don’t know, this weight comes all over me, I can actually feel it.”*

#### **7. Barriers to accessing treatment**

Resistance from the person they are caring for, lack of information as to where to go for help, poor diagnostic skills among some health professionals and services, and stigma are mentioned as potential barriers to accessing treatment for a family member with an anxiety disorder.

*“I was relieved when he had the diagnosis because at least we know what we’re dealing with. It’s unfortunate that it didn’t happen the year before – it would have saved a lot of suffering and heartache.”*

In the absence of professional intervention, carers often assume responsibility for their family member, leaving many feeling out of their depth, overwhelmed and unsupported.

*“They leave the onus and the responsibility to us. And it’s a nightmare.”*

Once professional support services have been accessed a number of factors continue to hinder accessing effective intervention.

These barriers relate to lack of inclusion of carers in the treatment process, the cost of treatment, ineffectual health professionals, proximity to services and lack of adequate services.

*“Look I understand, I mean there’s confidentiality... I understand all that. But you know I think they need to take on board that you’re the one he’s seeing with the information...”*

*“Psychiatrists should specialise like medical professionals do.”*

Carers commonly considered effective treatment for their family as the most significant means of alleviating the strain they experienced in their role.

*“What would make the difference is proper treatment. If they’d have had proper treatment back in the early days, the problems would alleviate themselves.”*

## 8. The need for support

The overwhelming nature of the role of caring is often compounded by the lack of professional help available for someone with an anxiety disorder. As a result, carers were left feeling in need of support and understanding. In a number of cases this support was absent from usual support networks such as friends or family. Consequently, the majority of carers sought support through more formal channels such as via carer support groups.

*“That I actually had a little bit of support there (at the support group) ... was just wonderful, and to just be able to talk and say how I felt, and just get some reassurance and support. That was fantastic.”*

## Conclusions

Anxiety disorders have a profound impact upon the carer and families – from the early signs of development and the detection process through to the more severe debilitating stages of the disorder.

The nature of living with the disorder itself coupled with barriers to accessing treatment leaves carers feeling depleted, overwhelmed in their role and in desperate need of support themselves.

Based on the experiences of carers who took part in this study, the needs of carers and families appear largely unrecognised or ignored by health professionals, services and the wider community.

## Recommendations

- Increase community awareness about anxiety disorders and the signs and symptoms associated with them.
- Increase community awareness and understanding about the significant impact anxiety disorders have not only on the person who has the disorder, but also those who care for them.
- Recognise the needs of carers and provide support when they are dealing with the implications of an anxiety disorder and the profound impact the condition can have on the individual and family.
- Review health policy pertaining to anxiety disorders management practices and carers’ needs.
- Encourage health professionals to better understand and respond to carers’ needs and concerns, and to promote a more inclusive approach to treatment and management.
- Ensure that appropriate support services and networks for carers in metropolitan and rural areas are adequately funded, available and accessible.
- Educate and encourage health professionals to share information with carers about the disorder, its management, coping strategies, information about appropriate services, and eligibility for assistance including mutual support programs and financial entitlements.

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](mailto:nicole.highet@beyondblue.org.au)

To view the full report online: [www.beyondblue.org.au](http://www.beyondblue.org.au)

**The Network of Carers of People with a Mental Illness**

Telephone: 03 9889 3733 [info@carersnetwork.org](mailto:info@carersnetwork.org)

To view the full report online: [www.carersnetwork.org](http://www.carersnetwork.org)

**Anxiety Recovery Centre Victoria**

Telephone: 03 9886 9377 [arcmail@arcvic.com.au](mailto:arcmail@arcvic.com.au)

To view the full report online: [www.arcvic.com.au](http://www.arcvic.com.au)

**Eating Disorders Foundation of Victoria**

Telephone: 03 9885 0318 or non-metro: 1300 550 236

[edfv@eatingdisorders.org.au](mailto:edfv@eatingdisorders.org.au)

To view the full report online: [www.eatingdisorders.org.au](http://www.eatingdisorders.org.au)

**Carers Association of Victoria**

Telephone: 03 9396 9500 Freecall: 1800 242 636

[cav@carersvic.org.au](mailto:cav@carersvic.org.au)

To view the full report online: [www.carersvic.org.au](http://www.carersvic.org.au)

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