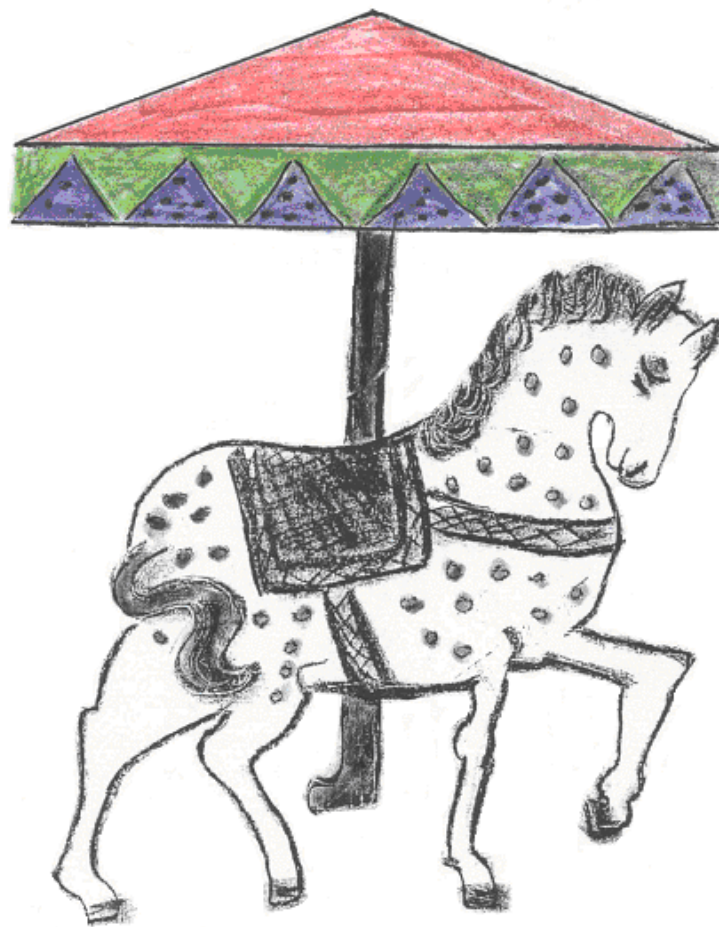


# The 'Ups and Downs' of Bipolar Carers:

An investigation into the coping  
strategies and needs of bipolar carers.

Lesley Jenkins



<b>Contents</b>	<b>Pg.</b>
Acknowledgements	3
Language and the Illness Model	4
Preface	5
Introduction	7
Aims	11
Method	12
Participants	14
Findings	15
Summary of Findings	26
Discussion	28
References	31
Useful Information and Resources	32
Appendix 1 - Interview schedule	34

## Acknowledgements

I would like to thank the bipolar carers for the outstanding contribution they gave to this research, my fellow researchers, who during our training days were a source of strength, reassurance and fun, Manic Depression Fellowship Wales (MDF) who helped me source participants. I would also like to thank Rachel Waters, the Research Training and Support worker for Wales, who gave much inspiration when it was needed. Lastly I would like to say thank you to my family, especially my husband Bryn, who has been very supportive and encouraging throughout the whole process.

## Language and the Illness Model

Language and terminology in mental health - or rather, mental illness - is fraught with differences of opinion and ideology, and different preferences for expression.

Many people adhere to the medical model, the dominant view in psychiatry, that there are mental illnesses in much the same way as there are physical illnesses or disorders. Within the medical model, bipolar disorder (or manic depression) is seen as a bio-chemical disorder, and many people find this a useful way of thinking about their experiences.

However, many other people do not, wishing instead to challenge the way the medical model encourages professionals to label people within a restricted set of categories and treat them accordingly.

This particular report tends to use the language of the illness model as this is the preference of the author and most of the participants.

It is hoped that the experiences and coping strategies shared in the report will be of use to all carers of someone with bipolar disorder, regardless of their individual ways of understanding and describing their experiences.

## Preface

Bipolar disorder is a unique illness. It not only affects every aspect of a person's emotional life, but also his/her carers relatives and friends.

My carer and I have first hand experience of bipolar disorder and understand the strain and isolation this illness can bring. It can be a complex, baffling illness and cannot be underestimated. It plays havoc with family life.

As a sufferer of bipolar disorder, the results and findings of this research will be of great interest to my carer, family, friends and me. It will also be of interest to the carers I interviewed and I hope it will be of significance in the mental health field.

My personal experience of bipolar disorder is that of my family in chaos. Living with this illness has had a detrimental effect on my carer's life and my own. It goes without saying that in many cases, bipolar disorder places a heavy strain on marriage/partnership, family life and friendship. Carers may witness mayhem and have to deal with all forms of uncharacteristic behaviour and for many carers the illness totally transforms their lives.

I developed this research to explore the experience of bipolar carers and their needs. I chose to do this project because my own personal experience and knowledge of the illness has given me an insight into the needs of the bipolar family. From my own experience and involvement with other carers and sufferers I recognise that there is a great need for more information, even training to support and improve the quality of life of carers and their families.

Carers need to gain more understanding and learn more about the 'ups and downs' of this bio-chemical illness which varies in ferocity from individual to individual if they are to help or make a difference to their lives, their loved one, and to all who are involved.

*'The help I most needed was to have things explained to me'  
(carer participant)*

Many publications are available to help carers in general who care for people with mental health problems, but there is no substitute for an educator/learner environment (one cannot ask questions of a book). Carers need to learn from other men and women with experience of the illness and from each other. My husband Bryn (my carer), envisaged with my help, a training course specifically designed for bipolar carers, devised, developed and delivered by my carer and I.

My research would contribute much towards the writing of the course and would be utilised to the fullest extent in the initial planning of the course.\*

Being a user researcher has been intellectually challenging and stimulating. I believe it has certainly helped participants to share their experiences with me knowing that I have 'been there'. It has also been a very humbling experience, listening to their responses.

Falkner & Layzell (200) also agreed that studies are politically powerful when they are user-led, and that there is evidence to show that participants are much more honest and give more information when they know that the researcher has had experience of mental distress.

Each stage of the research brought its own difficulties; the planning of the research did not match the carrying out of the research. For personal reasons I had to take time out, and some aspects of the research - the analysis and writing up- took much longer than I had anticipated.

However, working on the project has been a very rewarding experience for me. Meeting other carers has been a very comforting experience but also harrowing at times. Coming together with other researchers has been very stimulating.

I am very grateful to the bipolar carers who have gladly shared their knowledge and experiences with me.



---

\* Please see information on The Bipolar Trust UK (charity registration number pending) at the end of this report.

## Introduction

The Mental Health Foundation's Strategies for Living project has been supporting 17 user-led research projects in the UK, of these 6 were based in Wales.

The research agenda in mental health is usually set by mental health professionals, who often have different priorities and understandings than users and/or carers. This project enabled mental health service users to set their own agenda for research and to design and carry out their chosen research themselves. Each one of these projects was designed and implemented by people with personal experience of mental or emotional distress.

This project differs from the others because it investigates the coping strategies of *bipolar carers* and discovers what information and services they need to cope more effectively

### *What is bipolar disorder?*

In his book, 'The Bipolar Disorder Survival Guide', David J. Miklowitz (2000) gives the following definition:

*'Its key characteristic is extreme mood swings from manic highs to severe depressions...It's called bipolar because the mood swings occur between 2 poles - high and low - as opposed to unipolar disorders, where mood swings occur along only one pole - the lows.'*

*'In the manic high state, people experience different combinations of the following: elated or euphoric mood, a decreased need for sleep, grandiosity or an inflated sense of themselves and their abilities, talkativeness, racing thoughts, an increase in activity and energy levels, changes in thinking, attention and perception, and impulsive reckless behaviour. These episodes may alternate with depressive episodes in which a person becomes depressed, often loses weight and appetite, feels fatigued, has difficulty sleeping, feels guilty, has trouble concentrating or making decisions and often feels like*

*committing suicide'* (Pg15). The periods between episodes are symptom free in some people.

Episodes of bipolar vary greatly from person to person, some accelerate into mania in stages, and some spiral into depression gradually. It is a very individual thing.

This research is important because it will increase the profile of bipolar carers generally, and more particularly make service providers more aware of bipolar carers and their needs. It will also serve to educate the public about bipolar disorder.

### *Caring and Bipolar Disorder*

Many studies have explored caregiving for chronic mental illness, especially schizophrenia, but very few have examined specifically and exclusively the affinity between the bipolar carer and sufferer, and the carer's needs.

One study which explores caregiving for someone with a severe mental illness per se is 'The Silent Partners', an overview of a survey into carers' needs by Hogman and Pearson (1995) where 92% of participants cared for people with schizophrenia, 3% bipolar disorder and 5% other severe mental illnesses. Hogman and Pearson acknowledge:

*'Every carer has individual caring responsibilities and individual caring needs' (pg. 4)*

Hogman and Pearson's study focuses on the mental health carer and his/her needs and gives carers the chance to talk about their individual experiences and feelings.

Another study by Hare (2002) comments on the enormous number of people in the UK who are committed to caring for someone with a mental illness, and recognises that carers need a whole range of services including emotional support, information and crisis advice.

Much research has concluded that mental health carers have not been given high enough priority by local and health authorities, and that they are used as unpaid labour.

Carers seem to be an army of free support saving the Government billions of pounds. 'Services are naturally centred on the patient, whilst the carers' needs are neglected...Rather than being valued, carers are taken for granted' (The Silent Partners, 1995, pg. 6)

However, on a more positive note, the 'Strategy for Carers in Wales' (2000) has recognised that:

*'Carers have a right to see their own health and social care needs met' (pg. 11)*

Many studies have found that caring can have a detrimental effect on carers' health. Henwood (1998) in his report 'Ignored and Invisible' revealed that 52% of mental health carers had been treated for stress related illness since becoming a carer.

### *Carers Information Needs*

Previous research suggests that an important need for carers is information. 'Caring About Carers', A Strategy for Carers in Wales (2000) agrees that more information is needed 'to know how best to respond to these needs for information and other forms of support'. (pg14)

It also recognises that:

'The provision of easily accessible relevant factually correct information is of critical importance to carers'. (pg14)

*'The Adult Mental Health Service in Wales Strategy Document' (Sept 2001) acknowledges that carers 'should be seen as partners in the care process, their views should always be taken seriously and they should be helped to understand how the problems can be managed to secure an effective outcome.'* (pg. 28)

Much literature is available on the type of support needed by carers and how they would like to be helped by health professionals.

Many carers have community psychiatric nurses (CPN's) who provide much support and advice to carers and their families. Unfortunately this service is not available to all carers, but many carers would appreciate this service.

### *Care Plans*

Care plans have been introduced:

*'to ensure that users of mental health services should have a comprehensive assessment of their medical, psychological and social care needs.....The care plan should provide details of the full range of care and*

*support services required and to be provided' (Adult Mental Health Services for Wales Strategy document , 2001, pg. 24).*

*This document suggests that 'all users be offered a written care plan...and where appropriate the carer...The care plan must be drawn up in collaboration with users and carers and must be regularly reviewed.'* (pg.25)

Unfortunately, Woof, Schneider, Carpenter and Brandon in the Journal of Mental Health (2003), observed that when carers were aware of care plans, some carers still had insufficient information about care plans, medication and complaints procedures. These findings in the Journal of Mental Health have implications for mental health services and how they might improve their provision for carers.

#### *Carers' Assessments*

The Practitioners Guide to Carer's Assessment (2000) proposes that the carer's assessment is undertaken at the request of the carer *'to determine whether the carer is eligible for support, what support is needed and to ascertain if these needs can be met by the services'* (pg6). The assessment should *'recognise the carer's knowledge and expertise'* and *'must focus on the outcomes the carer would want to see to help him/her in the caring role and maintain their own health and well being.'* (Pg7)

Despite the large amount of evidence concerning the needs of carers, recent research suggests that carers' needs are still not being met. This study is likely to add to the weight of evidence available to support the argument for more effective support for carers. It is specifically based around the needs and experiences of carers in Wales. This study is particularly powerful because it is user-led research. There is evidence that participants are more honest and give more information when they know that the researcher has experience of mental distress and hence some shared understanding of their circumstances (Faulkner and Layzell, 2000).

## **Aims**

This research project has the following aims:

- 1) To explore the experiences of bipolar carers and their needs.
  
- 2) To raise the profile of bipolar carers within the mental health services and to make the health services aware of what services and information bipolar carers need in order to cope more effectively.
  
- 3) To educate the public about bipolar disorder.
  
- 4) To combat age-old prejudices and stigma born out of ignorance and fear of the unknown.

## Method

As a fledgling researcher and knowing little about research methods, my original plan was to interview about 50 carers. However, on learning what was involved - the different approaches, interviewing techniques, designing and writing a questionnaire and analysing, not to mention writing up the report - I quickly changed my mind and decided that 12 would be a much more manageable number. It turned out that I was able to find 13 carers who were keen to participate so the number became 13.

I planned to take a qualitative approach and use semi structured interviews which I hoped would produce extensive wide-ranging answers to my questions. This would provide me with a wealth of information to analyse.

The participants were people who were caring for a person who suffered with bipolar disorder living in the South Wales area. I was lucky to find carers from all walks of life who were prepared to take part. Husbands, wives, partners, mothers and children were represented.

I began the research process in February 2002 and completed it at the end of July 2003. Because I was involved in other work I had to take time out for longer periods of time than I had anticipated, which meant I had to work long and hard to finish the research by July.

The participants had the choice of being interviewed at my home, at their own home or at a Mind office. All but 2 preferred to be interviewed in their own homes. Although I had to consider personal safety issues, I felt comfortable about doing this as some of the participants were people I knew or who were friends of friends. Giving an interview at home, the participant would be more relaxed in his own surroundings and would probably feel more confident and at ease during the interview.

As a sufferer of bipolar disorder and former Chair of a MDF self help group, I knew a handful of carers. I approached them and asked if they would like to be involved in the research. This netted me 4 carers to begin with. MDF Wales gave me permission to approach other MDF self help groups to access more carers.

I gave talks at two MDF self help group meetings and at a carers meeting where I was able to approach more carers to be involved. I wrote an article for a mental health information newsletter and one carer approached me after reading this. The last 3 carers, were more difficult to find. These came about as suggestions from carers already involved. By September I had completed in depth interviews with 13 bipolar carers. The participants were not intended to be a representative sample of bipolar

carers, but there was a range of ages and type of caring relationships included.

The interview questions were framed to gather information on how the illness affected the carer and family life, how the carer coped day to day and in times of crisis, how caring had affected the carers health and employment and what information and support needs they needed to help them to cope more effectively.

Simple, straightforward questions were asked first e.g. *'Are you a full-time or part-time carer?' and 'How would you describe your partners health at this time?'* followed by more complex ones such as *'How did your family and friends react to your partners illness '* and *'How do you cope when your partner is very ill?'*

There were some difficult areas for the participants and for myself. Some of the participants felt the need to offload to me about their experiences some of which were quite harrowing and unnerving for both of us. However, all participants and I managed to keep our composure throughout the interview, though at times it was tough.

### *Analysis*

I did my own transcribing. This helped me to get an impression of the transcripts straight away, and I quickly got to know them very early on in the process. The main disadvantage of transcribing myself was the time it took - 5 months. It was very intense and tiring.

I tried to reduce bias in my research through taking a reflexive approach. I identified my own views and experiences relevant to the topic and made a note of them. I was careful with the wording of the questions and I was also mindful of my own reactions to the questions. I did not want to influence the participants in any way. I was very aware of my own views throughout the analysing and looked carefully at the analysis to make sure that I tried to reduce bias in this research. I incorporated some basic numerical techniques such as counting the number of participants who expressed certain views to ensure that I had got an accurate impression.

The analysis was carried out in conjunction with the Research Training and Support worker from Strategies for Living, including cross checking of themes to further ensure reliability.

My themes emerged quite naturally and tended to arise from the subject matter of the questions. I grouped several questions around the carers' health, family life, and employment and it became obvious that these subject areas were to become my more important themes.

I ensured confidentiality by keeping all transcripts in a lockable cabinet and destroyed all tapes after use. I explained the procedure to all my participants. Confidentiality was of special concern to all taking part.

After interviewing, the participants were given a thank you card and £10 to thank them for taking part.

I enjoyed the research very much although it was more involved than I had thought and was very hard work; it was a very positive experience.



## The Participants

The participants in this research all provide care for someone who suffers with bipolar disorder. Although many of them are spouses, some are sisters, daughters, mothers and partners. Not all carers live with the sufferer but they are all main carers in the relationship. The age of the carers ranged from 21-79+ years and the age of the sufferers from 34 - 60+ years. The length of time caring ranged from 1-40+ years. Just under half of the participants were in full time employment, 3 were in part time employment, and 4 were not working - of these 3 people were retired.

## The Findings

Some strong themes emerged from the analysis process. These included the effects of caring on the carers' health, family, employment, and the need for more assistance from the services, coping strategies and the need for information.

### The effects of caring on the bipolar carers health

12 of the 13 carers felt that their caring role had resulted in problems with their own health. When asked about the effects of caring on their health, carers identified stress as the most common complaint.

*'It's been a huge strain – very stressful. Especially the last episode. I was very anxious and stressed'*

*'It was very distressing really because you didn't know what was happening. I didn't cope very well at all, at first, because it caused stress and friction.'*

More than half of the carers suffered with loss of sleep, especially when the person they cared for was manic.

*'When she's manic I can't sleep, when she's in hospital I can't sleep- thoughts going through my brain.'*

*'It's definitely made a difference with regards to sleeping. If he gets up early, he expects me to get up early as well. But I often need to go back to sleep.'*

More than half of the people interviewed cited anxiety and depression as an effect of caring.

*'It's been very stressful during manic episodes. I've been on Seroxat (antidepressant) for depression myself. It's been very hurtful and painful.'*

*'When he's been depressed for a long time I get depressed too, because I can't cope with it all. I can cope as long as I know he's getting better eventually, but if it goes on for a long time then it gets me depressed.'*

### The Sufferers Health.

Carers were also asked to describe their sufferer's health at this moment in time on a scale of 1-10. 10 being excellent and 1 being very poor. Their replies ranged from 2-9. Many carers acknowledged that the people they were caring for were 'well at the moment' or that 'mental health changes'. They were also asked to describe their sufferer's illness in terms of severity and frequency of episodes over time. 5 carers said that the illness had become more severe and/or more frequent. 2 felt that the severity and frequency had stayed the same.

However, a few respondents felt that their sufferer had less severe and less frequent episodes of illness than in the past.

*'The severity has changed. Before I knew him he had very high episodes, which he hasn't had since I've been with him'.*

*' Since we've joined the Manic Depression Fellowship (MDF) it's made a huge difference, (to her episodes) Self-management skills she's acquired. She's been within the normal mood range now for a year or two'.*

Apart from joining the Manic Depression Fellowship, which did seem to make a difference to some sufferers, there did not appear to be any particular trend as to why the sufferer's health improved or worsened.

### Effects of caring on family life.

Caring for someone with bipolar disorder undoubtedly places a heavy strain on marriage/partnership, family life and friendship. Just under half the participants felt that caring for someone with bipolar disorder affected their relationships with each other and, with family and friends in an adverse way.

*'When she's been high she's been quite blunt with a relative. She has upset quite a few people when she wasn't well, so people keep away'.*

A number of people felt that their social lives had been inhibited and many felt isolated.

*'It has taken some of the enjoyment out of my life because when my partner is ill we can no longer go out as a couple, so we don't really have a social life'*

*'Because of her frequent bouts her general behaviour was erratic. It wouldn't do to go out in the evenings with friends'*

3 participants had lost contact with friends as a result of the illness:

*'Years ago people used to move away from you – afraid they would catch it'*

Others had difficulties with, or very little contact with (some) family members:

*'Certain members of my family are understanding. Mam's side are great - not so good on dad's side'*

*'My mother told me not to marry her – said I'd have a life of problems'*

One participant had no family living near to help:

*'No family near – we send cards but no practical help from the family'*

However, on a more heartening note, 7 people commented on the outstanding support they received from family and friends.

*'Our network of friends were very supportive and when my wife was first diagnosed our son was a good support'*

*'My two sons and daughter kept an eye on me'*

*'Our friends and family were 100% behind my mother'*

*'If we didn't have friends it would have been difficult. We are lucky because we have a network of friends'*

## Effects of caring on employment

The majority of carers said that their work was badly affected and that they had to take time off when their sufferer was very ill.

*'Yes, it has affected my ability to work. Although my job is not hugely demanding it's a good thing that it isn't.... I've had to take time off work. Especially the last episode. My children started to play up. I've also said that I felt ill when I didn't to take time off to look after my brother'*

7 people reported that their ability to work was affected as a result of caring. One carer talked about *'losing confidence'* and *'the ability to concentrate'* and *'to think of jobs you can handle'* when her son was ill.

For some 3 carers early retirement seemed to be the only option.

*'I had no support, none at all. In fact I gave up work – stopped early. One of the reasons being, the pressure of being a carer'*

For carers with a family, especially young children, caring and working was *'very exhausting and difficult'*. Those with young children seemed to be the most badly affected:

*'But it wasn't just taking time off work, it was trying to look after the children while still working – very, very hard indeed. A tremendous burden on my work'*

However, 2 participants talked about how having a job helped them cope. One carer talked about her *'low stress'* job with *'little responsibility'*.

*'Sometimes it helped just to go to work and to be with young children?'*

*'My job helped in some ways. The interest – it forced me to concentrate. Work was a help, a sense of balance, normality and order?'*

The majority of working participants were in full time employment. Being a carer and holding down a full time job is a formidable, demanding task in itself, but some carers also had young children to attend to whilst others were just children themselves caring for a parent as best they could.

## Services Needed By Carers

The types of services carers felt would be helpful varied considerably and included both emotional and practical features.

### Professional Involvement

Some families received support and guidance from a community psychiatric nurse (CPN) while others did not. 10 participants mentioned needing more information from professionals concerning prognosis. They wanted to know what to expect.

*'It is difficult. If only I'd known what was going on'*

### Counselling

2 participants were receiving counselling whilst another 5 would have liked counselling to be available to them.

*'Recently I've had to ask for outside counselling to enable me to clarify what's going on and how to problem solve'*

### A Care Manager

One carer mentioned the need for a care manager *'to look after the practical and emotional needs of the sufferer'*

However, one person felt they had received first class attention from services in their area. This carer said:

*'The hospital observed him and I was given all the information at the time, and I was able to ask questions'*

Some carers would have liked someone there to provide support and information.

*'I would have liked someone to turn to so that I could have been helped'*

*'It's an extremely serious and dangerous illness. Someone should be involved immediately, someone who knows what's going on'*

## Other Helpful Services

23% said that some form of help would have been beneficial: *'practical help with the children, cleaning and cooking'*

One participant would have liked *'someone to do the shopping or to take the sufferer swimming perhaps'*.

## Respite Care (a break in caring)

Respite care was not available to most carers. Only one had received respite care. They commented:

*'When working it was a tremendous help to my career and life.'*

The majority declared they would have liked to have received it if it were available, and some also mentioned what form they would like it to take.

*'It would have been lovely to have received it. If I was finding it stressful or if I wanted to go shopping'*

*'If I were confident that there was a place where he was well looked after, trained medical staff perhaps.. I would have liked to have this available.'*

However 2 people felt they did not need respite.

*'Respite care? No it does not apply. If she's very ill she ends up in hospital'*

*'Over the years she has been so ill that she has gone straight to hospital, so we haven't had the need'*

## Coping strategies

In my study I defined coping strategies as ways of dealing with a situation more competently. Coping strategies can be regarded as skills, activities or ways of thinking about things that can be used to help a person cope more effectively.

## People to talk to

The carers were asked how they coped when the person they cared for was ill. Many carers said having people to talk to was a major part of their coping strategy.

*'His family were a great help – his mother especially'.*

One carer felt she could talk to family members who were informed about the illness but that it was harder to talk to people who did not have much knowledge about it.

*'Certain members of the family were understanding, listening etc.. I wouldn't be able to talk to others who don't know much about it. People are frightened of the unknown. They show things on TV – sensationalise them. It's not so good'.*

## Friendships and Hobbies

The vast majority of participants (12) stated that friendships were very important and that they relied on friends for help and support.

*'My friends were very supportive and very understanding and caring'.*

*'My husband and I have a lot of hobbies and friends. When our son is very ill we don't have time to see our friends. We do have a social life – coffee and meals but when he is very ill they step back and don't come and see us'.*

(This carer felt that her friends stepped back in a helpful way and understood that she wasn't able to see them when her son was ill.)

However 2 people said that they did not talk to friends as a way of coping.

*'I don't talk to many people – it's confidential. I find it difficult discussing it with others'.*

*'I don't have many friends. It's difficult to form friendships because of the frequent bouts'.*

One carer talked about the reaction of friends to his wife's illness and of the isolation it can bring.

*'At first it was something strange. No one had ever encountered it before. It was difficult to comprehend – 'pull yourself together' – I got that sort of thing. People didn't understand at first'.*

Carers talked about other things they did to help them cope. Two carers took over the cooking chores and other household duties, or used take-aways to enable the house to run smoothly while their wives were ill.

*'dinner to cook, shopping and cooking to do, so you took over those roles - you have to don't you?'*

*'you go to a take away. Sometimes I cook if she is not well'*

Two carers talked of being on 'automatic pilot' when the person they cared for was ill.

*'you just get on with things and think about yourself later'*

*'when he is ill, I just go on auto pilot, then weeks later I take sometime for myself, whenever I can'*

Conversely, one carer talked about having 'her own space'.

*'I need to look at my own needs. So if I want time out, time to rest or cope, I talk to my partner... we have an agreement that I can have my own space within the house and he can have his'*

Some carers felt they were not employing any coping strategies, they felt they were *'just getting on with it'*, while others had many hobbies such as sport, walking, driving or swimming and these were most helpful coping strategies.

*'I go for drives every afternoon to be quiet and alone'*

*'I also have hobbies, I cycle, swim and walk and have an active social life'*

*'I have long hot baths - aromatherapy - I go for drives and walks and laugh about it sometimes'*

Some carers had dogs and enjoyed going for a walk with them. *'it seems to help'*

*'I go out of the house sometimes - walk with the dog. I try to look forward that things will get better'*



One carer admitted turning to alcohol for solace:

*'I drink too much and then I'm bad the next day'*

He explained,

*'I try to squeeze a lot more fun into my life...I try not to think about it, but sometimes it doesn't work'*

Two carers reported that religion had a big influence on their role as a carer and helped them find strength to cope.

*'I have a very strong Christian faith. I leave all my situations to God. It has enabled me to cope. I was never let down. I was never worried. I had that strength'*

*'I've become more religious. It doesn't prevent me from being frustrated and unhappy, but more acceptance'*

Acceptance was a big concern for another carer who felt that being able to cope depended on acceptance:

*'To accept the situation, not to resent it or fight it, come to terms with it and live within the limitations it imposes. If you can do that you're half way to winning the battle, but I shudder to think how you'd be otherwise- you could give up'*

Many carers said having people to talk to was a major part of their coping strategy. Family and friends were the main source of strength, however, 2 people found that talking to a counsellor or psychologist also helped.

*'I've been able to see a counsellor. If I hadn't it would have been a big problem'*

Some carers also talked about the isolation that caring for someone with bipolar disorder can bring. They expressed the need to share stories and experiences with other carers.

*'It would be very valuable if there were carers meetings every 3 months or so, to get together and unload'*

## Support

Many participants felt that they had no support.

*'no support really - had to adapt to looking after myself. The boys rallied round. I supported them as much as they supported me. I sought to maintain my independence although it has been a severe limitation'*

*'I had hardly any support. I wasn't told very much. There was no support'*

In contrast as stated earlier, many participants had extensive support from family and friends.

## The Need for Information

The need for information was of paramount importance to all carers. All carers interviewed stressed the need for more information about the illness.

*'I wasn't told very much. No information about the illness'*

*'Information and knowledge about the illness is vital. You've got to be fully in the picture'*

All participants stated the need for more information of all kinds to help them understand the complexity and ramifications of bipolar disorder. 10 participants wanted more information concerning prognosis. They needed to know:

*'what to expect'*

*'It is difficult - if only I'd known what was going on'*

Carers were asked if they had ever received information on the following: prognosis, medication, provision of services, the nature of bipolar disorder, carers rights, how to care or genetic/hereditary factors. The results were as follows.

Topic	Number of people who <i>had</i> received information
Prognosis	2
Medication	8
Provision of services	3
Nature of bipolar disorder	5
Carer's rights	3
How to care	5
Genetic/hereditary factors	3

Over half the carers had received information about medication. Under half of the carers had received information about any of the other topics mentioned. The lowest figure was for prognosis.

The types of information people wanted varied greatly from general information about the symptoms and prognosis to how to cope with specific symptoms.

*"Information on the general nature and the signs would have helped me. The other aspect would have been a much wider knowledge about what treatment was available and what effects that treatment would have"*

*"I would have liked to have known what other route I could have gone down. What to do, where to go etc"*

*"when she was on a high, know ways of calming the situation down"*

*"I think it would be good to be informed that it affects different people in different ways...knowledge should be available"*

*"Insightful knowledge so that I could empathise with him"*

Eleven of the carers mentioned the need for 'better communication' between psychiatrist, GP, carer and sufferer. One carer suggested being provided with an 'information pack' and a book list which *'would be helpful'*, but was quick to add:

*"It's a bit difficult to find out the information to deal with a partner from a book"*

8 people felt the need for some kind training course to help them cope with their role. 4 said that some kind of training course would be helpful, 1 said that it would be very valuable, and 1 that it would be marvellous, and that they would like to go on such a course.

## Summary of Findings

Caring for someone with bipolar disorder has a profound, potentially devastating effect, not only on the carer, but also on the whole family.

The challenging aspects of caring for someone with this illness include loss of sleep, stress, anxiety, depression and inability to work.

These negative features of the caring role seemed to increase when the carer had dependent young children or if they worked.

Unpredictable or inappropriate behaviour when ill, sometimes seemed to cause rifts or isolation in some families. However, many carers benefited from very good supportive relationships with their families and friends.

These families and friends seemed to be more knowledgeable and understanding and so were able to give more support and understanding to the carer who can often be 'at the end of his tether'.

(69%) were in full time employment and some were struggling to cope with caring and working. It became apparent that most carers had taken time off work at some time during their caring.

In some cases, carers had no option but to take early retirement. Carers who worked and had children were very badly affected. Those carers who did not seem to be as severely affected were those who were self employed so the pressure of losing work was minimised or those whose jobs actually seemed to help them cope e.g. a low stress job with little responsibility or those with a job which seemed to help the carer cope by maintaining a sense of *“balance or normality”*.

It was also evident that the carer needs much information and reassurance not only from family and friends but also from mental health teams if he/she is to carry out the demanding role of a carer.

All carers seemed to have some coping strategies although they didn't all label them as such. A common strategy was **talking** to other people - this could be family, friends or professionals. 92% of respondents said that the support of friends was very important and that they relied on this.

Different carers seemed to take different approaches to coping. Some put their partner first and took time for themselves later when their partner was better; others found it important to take more regular time out for themselves.

Strategies included practical things such as getting takeaways instead of cooking. Many strategies seemed to help the carer to relax and stay mentally well - such as hobbies, social life, exercise, long baths, and walking the dogs. Others involved ways of thinking about the situation such as trying to see the funny side of things, accepting the situation as it is, and being optimistic. Several carers found their religious beliefs very helpful in coping and one carer said he/she used alcohol to help him/her cope on a short term basis.

Support and information about the illness is vital to all concerned. If the support and information is available to carers, then some of the negative effects of caring may be minimized.

## Discussion

Caring for a spouse or relative with bipolar disorder is often a demanding and exhausting responsibility. Carers often feel they are struggling against a system of insufficiency – their needs are not being met.

If the carer is to play a part and accept responsibility in the nursing, protecting and providing for his/her loved one, he or she must have access to up to date information concerning behaviour patterns which are likely to lead to episodes of bipolar disorder. The carer also needs continuing reassurance and emotional, intellectual support and practical guidance.

The stresses and strains, the sleepless nights, the severity and frequency of the episodes, and the amount of support and guidance all have a considerable part to play in the ability of the carer to care and cope with, not only the person he/she cares for, but also in maintaining his/her own health.

The effects of caring for a person suffering with bipolar disorder impacts on many facets of family life and cannot be overestimated. The need for support from the family of the carer and the mental health services is of paramount importance for a carer entrusted with the care of his/her loved one.

Many carers did not seem to receive adequate help, and continued in the same course of action with little or no practical or emotional help.

The evidence in this research supports evidence other studies have found e.g. M Henwood (1998) in 'Ignored and Invisible', that many carers felt stressed, anxious and often lost sleep. Some even suffered with depression. The carers' lives seem to be thrown into confusion and chaos as they try to make sense of what is happening.

Carers felt they needed more help from the services because their views, they felt, '*did not carry any weight*'. They also felt they '*should be consulted*'. (Henwood, 1998)

However, Pearson and Hogman (1995) in 'Silent Partners' also recognise that other factors could compound the health problems experienced by bipolar carers. Financial problems due to inability to work perhaps, problems with relationships, housing or social class. All these and more have their part to play and could cause additional pressure on the health of the bipolar carer.

Pearson and Hogman affirm that these causes aside, these problems do exist and that policy makers and the mental health services need to

*'identify what services are required to improve carers' physical and mental health.'* (Silent Partners, page 16).

It emerged that those carers who were blessed with the support and compassionate and concerned attitude of their family and friends, appeared to make out more favourably than those who did not receive support from their family and friends. Some carers remarked that caring would have been difficult if they did not have friends. They felt *'lucky'* to have a *'network of friends'*.

Some relationships with family and friends inevitably broke down. Some family and friends were lost because of uncharacteristic behaviour on the part of the sufferer, and the fear and ignorance of some family members and friends.

During the course of this research it has become clear that more services are required by carers than are available to them at present. Also some families receive considerable support while for others, the support was woefully inadequate.

CPN's give much needed support to bipolar sufferers, carers and their families. The value and importance of their role cannot be overestimated. It seemed that those carers who were not granted a CPN would have liked to have had one.

Services for carers did not seem to be available to all carers, and highlighted the fact that there seemed to be a discrepancy. Some families were not allocated a CPN, offered respite, advice or support. However in other areas carers fared much better. Where CPN's were available they were seen to be very capable, dependable and of great help to the carer, sufferer and family in general.

### **Training and Information**

Another ingredient on the carers *'wish list'* was the need for *'some kind of training course'* to help give carers confidence, competence and capability to deal with their demanding role. Also some carers expressed the need for contact with other carers to share stories and empathise with each other. A training course could fulfil these needs.

Knowledge is power and gives the carer a sense of control and enables them to make sense of, and to cope more effectively with the situation they find themselves in. Carers need information of all kinds and during the

course of this research it has become clear that a diagnosis of bipolar disorder needs to be confirmed as soon as possible so that the carer and the whole family can attempt to learn and understand the illness and have some idea of what to expect and what to do to help the sufferer.

It seems that if carers were given information on how the illness presents itself and what is likely to transpire, given up to date information on matters such as medication and side effects and also of new developments in medication it would have helped relieve the stress and uncertainty; it may have improved the quality of life from the onset of the illness.

Ignorance and misinterpretation of uncharacteristic behaviour, when the sufferer is in the grip of this formidable illness caused much distress to carers and their families. The stigma of the illness also seemed to be compounded when added to the lack of knowledge and understanding.

All sufferers were currently prescribed medication and the majority of carers stated that they were taking it. Medication was one topic on which carers wanted more information. The effects and possible side effects of medication mean that it is important to have sound and thorough information on this. When there is little or no information forthcoming, carers and sufferers may become cautious and wary of medications.

There was a need for better communication between psychiatrist/GP/carers/sufferer. This need seemed to be high on the carers *'priority list'*. Carers wanted *'to be accepted as part of the nursing team'*. This seemed to be the ideal situation for 1 carer, indeed, it could be *'very advantageous for all concerned'*.

## References

Faulkner, A. & Layzell, S. (2000) *Strategies for Living: A report of user-led research into peoples' strategies for living with mental distress. The Mental Health Foundation: London*

Henwood, M. (1998) Helping The Helpers *Community Care* 13.8.98, p. 22-23

Hogman and Pearson (1995) *The Silent Partners: the needs and experiences of people who provide informal care to people with a severe mental illness*. Kingston -upon -Thames: National Schizophrenia Fellowship

Miklowiz, D.J. (2000) *The Bipolar Disorder Survival Guide* The Guildford Press: London/New York

Miklowiz, D.J. (1997) *Bipolar Disorder- a family focussed treatment approach* New York: Guildford Press

National Assembly for Wales (2000) *Caring about Carers A strategy for carers in Wales, implementation plan* Cardiff: National Assembly for Wales

National Assembly for Wales (2001) *Adult Mental Health Services for Wales: equity, empowerment, effectiveness, efficiency strategy document* Cardiff: National Assembly for Wales

Woof, D., Schneider, J., Carpenter, J., & Brandon, T. (2003) Correlates of Stress in Carers *Journal of Mental Health* Vol.12, p.29

## Useful Information and Resources.

**The Bipolar Trust UK** (charity no. pending) is an organisation which has been set up by bipolar carers to help support and offer training courses specifically to bipolar carers and their families.

The course adopts a dual management strategy where mutual cooperation, respect and trust figure highly between carer and sufferer.

It is designed to give carers increased knowledge, information and suggestions to enable them to work more efficiently with their sufferers and to help prevent lengthy hospital stays.

For more information contact 01873 856314.

### **Manic Depression Fellowship Wales**

1 Palmyra Place  
Newport  
South Wales  
NP20 4EJ

01633 244244

<http://www.manicdepressionwales.org.uk>

[mdf.wales@btclick.com](mailto:mdf.wales@btclick.com)

Self help organisation for people with bipolar disorder, their relatives and friends. Has a network of support groups. Quarterly journals, fact sheets and publications available.

### **Carers National Association Wales**

River House,  
Ynysbridge Court  
Gwaelod y Garth  
Cardiff

02920 811370

[internet@carerswales.demon.co.uk](mailto:internet@carerswales.demon.co.uk)

**Hafal**

Suite C2  
 William Knox House  
 Britannic Way  
 Llandarcy, Neath  
 SA10 6EL

E-mail [hafal@hafal.org](mailto:hafal@hafal.org)

Website [www.mentalhealthwales.net](http://www.mentalhealthwales.net)

Hafal (meaning equal in Welsh) supports people with severe mental illness in Wales, and is part of Rethink the UK charity for people with severe mental illness.

**Department of Health**

[www.carers.gov.uk](http://www.carers.gov.uk)

This site provides information on legislation affecting carers

**Depression Alliance Cymru**

11 Plas Melin  
 Westbourne Rd  
 Whitchurch  
 Cardiff  
 CF14 2BT

02920 692891

E-mail [depress@lliance.fsnet.co.uk](mailto:depress@lliance.fsnet.co.uk)

Website [www.depressionalliance.org/wales/index.htm](http://www.depressionalliance.org/wales/index.htm)

**STEADY (support and Training for Elation and Depression in Youth)**

Vicky Lawson, Steady @ MDF  
 Castleworks, 21 St Georges Rd  
 London  
 SE1 6ES

08456 340546

E-mail [steady@mdf.org.uk](mailto:steady@mdf.org.uk)

Website [www.steady.org.uk](http://www.steady.org.uk)

## Appendix 1

### Interview Schedule

Do you consider yourself to be a part-time or full-time carer?

Do you live with the sufferer?

How long have you been a carer?

How long has the person you care for been suffering with bipolar disorder?

How old is the person you care for?

How would you describe your partner's (or brother, parent etc) mental health at this time? (on a scale of 1 to 10 where 1 is very poor and 10 being excellent. Tell me about your partner's physical and mental health.

What effect has being a carer had on you?

Do you feel that your caring role has resulted in any problems with your own health?

Has the effect of being a carer shown itself in any other way?

Have you ever had to take time of work due to your partner's illness?

Has being a carer affected your ability to work? - in what way?

What support, if any did you receive to enable you to carry on working?

Has the severity and/or frequency of his/her episodes changed at all over the years? (more or less severe, more or less frequent)

Do you think there is a reason for this?

Has he/she ever been sectioned? If yes, how were you helped?

Do you think certain situations may trigger an episode? (examples)

How did/do your family and friends react to your partner's illness?

How do you cope personally, how do you find the strength to cope when your partner is very ill? (family, friends, faith, services?)

What kind of things do you do to help you cope? (talking to others? Ways of relaxing/switching off?, hobbies?)

Are you aware of the medication your partner takes? Do you know if he or she takes it?

Have you ever received information on the following:

The future (prognosis),

Medication

Provision of services

The nature of bipolar disorder

Your rights as a carer

How to care

Genetic/hereditary features

Do you, have you ever and would you like to receive respite care - a break in caring?

If yes what kind - what form did it take, what form would you have liked it to take?

What kind of knowledge or information do you think would have been most helpful/ useful to know from the start when your partner was first diagnosed?

Is there anything in particular you would have liked to have known about the illness?  
Questions you'd have liked to have asked the CPN?

In an emergency situation (crisis) who do you contact first? (family, friends, services, GP, hospital, police, social worker)

If there was a course for carers, what sort of topics, subjects or advice would you like to see included?