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Research Is Everybody's Business! Seminar Series
Mr Bernard McNair & Dr Nicole Highet

"Consumer & Carer Perspectives on Depression:
A National Study" *25 March 2004*

Dr Kathy Griffiths
On behalf of the Consumer Research Unit of The Centre for Mental Health Research, welcome to this our fifth lecture in the series "*Research is Everybody's Business*". I would also like to add a special welcome to Ingrid Ozols, who is up here from Melbourne. Ingrid is the Chair of *blueVoices*, which is the Consumer Carer Advocacy arm of *beyondblue*. So, it's great to have you here Ingrid.

Now all to often mental health research is carried out without any real input from consumers who tend to be treated as passive subjects rather than people who can actively participate in the research process and contribute to it. By contrast *beyondblue*: *The National Depression Initiative*, have been very mindful of the importance of consumer perspectives and contributions in mental health research. Tonight we are fortunate to have with us, Mr Bernard McNair and Dr Nicole Highett from *beyondblue*, to speak about their research on the experiences and perspectives of consumer's and carer's with depression. Mr McNair is the National Co-ordinator of *blueVoices,* the consumer carer advocacy body that I was talking about before. He is also a board member of Lifeline Australia, a board director of the Neuroscience Institute of Schizophrenia & Allied disorders, past president of the Mental Illness Fellowship of Australia, past president of the Schizophrenia Fellowship of NSW, past board member of SANE Australia and a past executive member of the Mental Health Council of Australia. When he is not doing anything else, Bernard works in his day job as the Group Manager of the 400 staff of Wesley Health & Counselling Service at the Wesley Mission in Sydney. Dr Highett is the senior program manager at *beyondblue* and has a PhD in clinical

psychology. Among many of her other roles, she is responsible for *beyondblue's* community awareness programs, which I think have been highly successful. These include programs in the workplace, insurance discrimination (which is a very important thing that *beyondblue* has been involved in), the needs of consumers and carers, and also looking at program evaluations of *beyondblue's* programs.

And I think Nick and Bernard must have accumulated more frequent flier points than all of us here combined, since for some years they have been flying around Australia talking to consumers and carers about their experiences. So, now it is my great pleasure to ask them to tell us about what they found out.

Thanks

Mr Bernard McNair

Thank you very much Kathy for that introduction. It is wonderful to have the chance to talk about our research. Nicole and I have been travelling for about three years doing this research and other work for *beyondblue* around the country. The stories we tell tonight are from the consumers and carers who live with depression, anxiety and bi-polar disorder on a day-to-day basis. We are really very privileged to be the storytellers and we hope that we can do their stories justice this evening.

"Just put some lippie on love" – This came from one of our groups in South Australia a number of years ago and it really typified for us how little some people, some families and some health care professionals understand about the illnesses of depression and bi-polar disorder. If you can do something that is distracting everything will be OK and maybe it will just go away. I'm sure there are many in this audience tonight who would understand only too well that without the proper treatments (or access to proper treatments) and without the proper community understanding, there is no chance that these illnesses and more importantly the people who live with them, can be integrated into the society, as they so richly deserve to be.

Beyondblue was to be the major mental health platform of the proposed third Kennett Government. History tells us their was no third Kennett Government – I offer no comment what so ever – however the political successes in the Bracks Government recognised the merit of a program such as *beyondblue* was to be. In fact, originally, our program was funded by the Commonwealth Government of Australia and the State Government of Victoria. Over the years we have engaged with most of the State Governments and Territorial Governments in the

Country, the notable exception being the noble state of NSW who believes that a Black Dog will fix it! I must make a comment around Michael Wooldridge. Whilst there may have been criticism of Michael's behaviour as he was leaving Government, having worked closely with him for a number of years on the Mental Health Council, as well as *beyondblue*, he served nobly the needs of mental health in this country and I think deserves to be remembered well for that.

Beyondblue has five major priorities. Firstly - the destigmatisation of depression by increasing community awareness. Secondly, we want to promote the prevention of depression. Thirdly, and what our presentation focuses on tonight, promote consumer and career issues. We support research and promote primary care training and in all of those activities we have probably divided our energies and funding base fairly equally amongst them. In terms of engaging with the consumer and carer areas, what we have done is three very distinct efforts. Firstly - community forums. In the first year and half to two years of *beyondblue's* life, we travelled all around the country. I remember the first week we were in Burke on a Monday night and Darwin on a Thursday night. What we purposely tried to do in those communities, especially those outside of the urban areas that tend to get a lot of presentations and a lot of speakers, was to go into the rural areas and have people from the community talk about their experience of living with anxiety or depression in that local community. We had a very set format for our program. It was about an hour and a half program. Ian Hickie, who was the inaugural CEO of *Beyondblue* and who really is one of the giants of mental health anywhere in the World, would give a presentation. We always had a consumer from the community as well as a carer, a local GP, and I used to round out the night with talking about what we hoped to achieve with the engagement of consumers and carers. These were quite remarkable nights really, because often it was the first time that people had had the chance to talk about their experience as a consumer or carer, in the local community. One night is very clear in my mind, three years later (and I think it was one of the very first ones that you came to Nicole). We were in Traralgon in rural Victoria, and the gentleman who had been speaking from a consumer perspective had been the Human Relations manager of the private jail which started in that region. Rural Victoria is like most of rural Australia with very high unemployment rates and he was able to employ several hundred people, including members of the indigenous population who in some cases hadn't worked for five years or more. There was a lot of drama around it and this gentleman developed depression, quite severe depression which required hospitalisation. And people would cross the street to avoid seeing him when he was walking around the local town. Perhaps you can catch depression by contact in walking! But this man was able to speak about, for the

first time, how that had affected him. How people he had given a restart in life to had in fact chosen to ignore him when he needed help and support most. These were very powerful nights.

The focus groups – Nicole and I have run a number of focus groups around the country. We have done groups on unipolar depression, bi-polar depression and our current focus is on the lived experience of anxiety disorders. We believe there is some very powerful research coming out of that. We have a virtual network, which is an email based service, and I'll speak more about that later this evening, but if you would like to join our virtual network, which is a free service of course, there is a card outside. If you leave your email address we would be very happy to put you onto our service.

So, the methodology we used with our research groups. The focus groups - we've so far run 16 groups in both unipolar and bi-polar depression work that were for consumers. We have run 8 which were for carers. And we have had an average of 6 to 7 members in those groups. The groups have run on average for three hours. When we designed them originally they were for two hours. We quickly realised that the questions that seemed very straight forward to us were indeed straight forward, but the very interesting paths that people led us down have given us some of the most interesting parts of our research. We always make sure that people have time to talk because even thought we never set out to run therapeutic groups there is no doubt that these focus groups, for a number people, have become therapeutic and for a number of people it is the first time they have felt able to share their experience.

The public forums I have mentioned – we have had 27, both metropolitan and rural, with about 2000 participants and the model we spoke about. We have a very set set of questions, or at least starting questions with our focus groups:

- When did you first recognise something wasn't quite right?
- What did this mean to you as a carer or as a consumer? (depending on the group)
- How did this impact upon your relationship?
- How did you seek help?
- Did you leave it up to the other person?
- Did you not believe that it was going to happen?
- What was the impact on other members of the family?

The other questions were:

- What do you need from the healthcare system?
- How can you better included in the treatment process?
- What do you need from wider society? For the inclusion in society?
- What has and has not worked for you?

In terms of agencies and strategies - We are trying to illicit some personal strategies for coping, which we then wanted to share through the publication we write. And lastly:

- What would you like *beyondblue* to achieve for you to make your life as a carer or consumer more palatable?

We tried to cover a range of issues, and as I said previously, we got an awful lot of side roads which led us to some very interesting places. I'll now hand across to Nicole to speak about the direct results of the research that we've done and to break our presentation up we'll both share this.

Dr Nicole Highet
Thanks Bernard. I am going to present first of all the research data that came out of looking at unipolar depression specifically. First of all I'll look at the lived experience for consumers, or people living with depression themselves, and then I'll particularily focus on the lived experience for carers.

So, based on the data we transcribed, and evoked from the data key themes that came out of the research, the first thing that really came out in relation to people's lived experience of depression, was the lack of understanding in the wider community about this as an illness. In particular, depression is seen as a personal weakness, or a personal inadequacy, as opposed to an illness. So a person who said that they might suffer from cancer, or some other physiological condition would get a different sort of response than if they say they suffer from a mental health problem like depression. We've just scattered some quotes throughout the presentation tonight to really capture some of the key themes.

"Physical illness happens to me but depression is perceived to be a weakness in me"
"I'm sick of being told that it all just a case of my attitude and I need to pull my socks up"

We use these sort of quotes when we are doing training as well as to try and educate people, who might not have exposure to these illnesses, that you wouldn't tell someone with cancer or chronic asthma or arthritis to pull their socks up, or put some lippie on love. But this is the response people get in relation to depression because it is often seen as a weakness as opposed to an illness.

People also talk about their experience when coming forward and disclosing that they might suffer from depression. They describe the fact that people are often unwilling to acknowledge or accept that there might be depression in that person, and a there is a tendency to quite often brush it under the carpet and almost just pretend that it is not there.

"Friends don't understand, they don't visit me when I'm in hospital and they assume that I don't want to socialise"

How often do you see flowers and chocolates bought into a psychiatric ward? Again it is a different scenario for someone who is suffering or hospitalised for a mental health problem as opposed to someone in hospital for a physical health problem. Consumers also talked about issues in relation to discrimination in insurance. In particular they discussed how when they would try and take out either income protection insurance, health insurance, or even travel insurance, they were denied or charged very high premiums, if they disclosed that they had a history of depression.

"I have just tried to make a claim for my insurance and I have just been told that it won't be honoured and my premiums have been trebled"

Consumers also talked about the lack of choice of treatment s available to them because currently we have a very medicalised, medical model of treatment in Australia.

"I don't want to stay on medication, I hate the side effects. Is there nothing else?

"I cannot afford private health insurance so basically my only option for treatment is medication. I cannot get to see a psychologist for at least 8 months at the local hospital or clinic, what's the point?"

Consumers also talked about, not only discrimination in insurance but also in the workplace as well. And again, this largely comes from the fact that there is a perception that depression is a

weakness or a personal vulnerability as opposed to an illness and people don't get the same level of support. And that naivety can lead to clear cases of discrimination in the workplace.

"Now I am unlikely to be considered for a promotion, I am considered to be inadequate even when I'm well."

"I was asked to chart the days that I would be taking off sick over the rest of the year and when I couldn't do that I ended up losing my job."

And certainly in a number of cases, these have ended up in quite hefty court proceedings as result of clear cases of discrimination. There is also the perception - the issue around it being seen as a personal weakness - which results in heavy issues around stigma.

"I finally plucked up the courage to tell my manager that I suffer from depression and I was given filing to do."

In response, this has obviously given us a lot of direction for *beyondblue* and *blue voices.* About first of all the need to educate the community a lot more about depression and in particular promoting the lived experience of depression. We've also worked heavily with Investment and Financial Services of Australia, which is the peak insurance body. We are currently working with the Mental Health Council in an effort to rewrite the guidelines around insurance so that these people won't be discriminated against any more.

Just moving on now to what it is like for the person who is caring for, or living with, someone with depression. This came from a separate round of focus groups, again conducted nationally. Carers also reflected on the lack of understanding about the illness in the wider community and living with someone with depression, not really knowing what they were in for or what it might all mean.

"At first you keep hoping that something will snap and they will snap out of it. They are irritable, and angry and unpleasant to live with."

Carers also talked about the process of the illness and the impact on the person with the illness.

"I was confused. I wanted to know what was happening to her. What is it? Have I done something wrong?"

So quite often there was a tendency for the carer to reflect on themselves, and question whether they had somehow let this happen. Carers described not really knowing what the impact was going to be on their life.

"There is constant emotional tension. Everyday I wake up and I think what is going to happen today. What will they be like?"

"You can't plan to have people for dinner or going away. When we have it has ended up a disaster."

Carers also described the feeling of sometimes living on the edge of their seat.

"You have to be ever vigilant. Everyday there is a potential crisis."

This is a great quote, just showing the high level of concern, always looking out for the other person.

"When a dog goes to sleep and it's got one ear up. That's what it is like to care for someone with depression."

We also found (certainly research shows) that the high impact of living with someone with depression – particularly untreated depression for long periods of time – impacts on the mental health of the carer as well.

"You live each day feeling like you're walking on eggshells. I can't stand his suffering. I was getting severely depressed."

Carers also talked about high levels of grief, and described an intense period of sadness and loss when they came to realise, and accept, the impact that illnesses like depression have on the other person.

"This is not the person I married 4 years ago. He is just a shadow of who he was and that is sad."

"You grieve for the person they were, or could have been."

“Of course, as a parent you have hopes and dreams. That they will go to school or Uni. Now I just want her to be alive. You have to let go of your expectations and dreams for them”

Because of the lack of understanding in the wider community around mental health problems like depression, carers as a result often feel like they end up being the sole support, because no one offers the same sort of support as they might receive if their son or daughter or partner had a physical health problem.

“You ask your friends when you meet them how they are going, but they don’t want to ask you back how you’re going.”

And this really reflects how people are not comfortable or know how to respond or support someone, around the issue of depression.

“Our friends don’t understand. They get annoyed with us when we have to cancel an engagement, or can’t make it to dinner because my partner is not well.

“The phone calls and invitations stop, they get angry and frustrated with us, they don’t understand”

Carers also talked about the inadequate information, help and support available, not only to the person with the illness, but also to them as carers. They are finding it hard to know where and how to access care, in the first place, both for themselves and for the person with the illness.

“It is only through persistence that you can get any help. You have to fight all the way. They can’t manage it, you have to be there to fight for them.”

So carers often take on the role of accessing care, and in addition to obviously living with the day-to-day burden of the illness, this can obviously have major repercussions on the carers. There is also a lack of obvious support for a lot of carers.

“I’m exhausted, I feel like I work shifts. I come home from my work and enter the house and I feel like I am starting my next job caring for my partner. There is no time for me.”

Carers also discussed the fact that there is no inclusion or lack of inclusion of the carers in the actual treatment process. Despite the fact that carers are people who have access to a wide range of information and ongoing support, and go home and live with the person, they are still often excluded from the treatment process.

"As a carer I am not told anything. Yet we are the ones with all the information about how they are and have been and still expected to care for them."

I'm just going to hand back to Bernard now who is going to discuss some of the implications of this research, and where it has taken us in the early years of *beyondblue.*

Bernard

Thanks Nicole.

We set our goals and priorities from the research that we have done across two main areas; within health services themselves and within the broader community. Anything that we do at *beyondblue* includes the active involvement of consumers and carers in all aspects of our work. An example is the insurance council work. Ingrid has represented our point of view on that committee as well as work on the better outcomes in mental health program. Lara Bishop, who is here tonight, has been integral in the success of the postnatal depression programs, which *beyondblue* are actively involved in.

Within the health service, what we have done is try to develop more responsive primary and specialist care sectors. As you'd probably be aware, about 75 per cent of people who do receive mental health care in this country get it from their General Practitioner and we've worked with the various colleges of General Practice to give them [the GP's] a better understanding of what people need. We've also worked within the specialist care sectors. We've educated health professionals so that they don't contribute to the stigmatisation of persons with anxiety and depression. Some of you may be aware of the very famous (but fairly hush hush) report about 8 or 9 years ago of Frank Small and associates, which was commissioned by the Federal Government. It actually pointed out that we mental health care professionals were the major source of stigma for people suffering mental illness. Not one of our proudest moments I'd have to say.

We work hard to provide more information about available services and treatments. In fact our current project is one that is stirring up a little interest out their in the broader community. We have been told by so many people that we work with that a good GP, a good psychiatrist, really

does keep you going, that they support you, motivate you, do a whole range of good things. But to find people of that calibre is becoming increasingly difficult. Despite our best efforts of lobbying the various colleges, nobody wants to even tell us who is available through the better outcomes in mental health program, and who has done the training so that they will be more responsive to mental health. This has been a source of great frustration to people we work with, so three weeks ago we launched through our virtual network, a call to people to tell us about health care professionals who care for them who are empathic, who offer good service, who bulk bill and who offer a service that makes them feel valued as a human being. We've collected about 150 referrals so far and once we have gotten permission from those practitioners, their names will go up on our website. It would be fair to say that we have also had a couple of fairly less than happy learned colleges. We've 'broken privacy', we've 'been bastards' in fact except for 'kicking the cat', we've probably done a few things that have annoyed them. That's good! I really hope that by the time we finish this little project we'll embarrass these people who live by the public purse, to put their names forward to care for people appropriately. We make no apologies for annoying them.

We've developed education resources for the wider community, around common symptoms and how to access, what we know at this stage as appropriate care. Nicole has written a magnificent workplace program, and the Australian Taxation Office, to their great credit, have engaged us to run workshops around the country for Australian taxation officers. We've run 50 or 60 so far, very successfully, just talking about the symptoms of depression, how to work with someone in the workplace, how to encourage them to get help. And that's a very strong part of our public awareness work that came out of what we discovered from our research around workplace discrimination. We are trying to get the responses changed to the insurance discrimination. Thanks to the hard work of Ingrid, Nicole and our colleagues at the Mental Health Council there is now a memorandum of understanding with IFSA, about ending discrimination in insurance. They were basing their figures on 30 year old, out of date actuarial figures and actually had no consideration of how modern treatments changed the outcomes quite dramatically for people. In fact in the great state of Victoria, if you happen to have acknowledged that you take antidepressants and drive a car, you're car insurance is 3 times what it is for those who don't take antidepressants!

We've certainly been engaged in advocacy for improved access to non-pharmacological forms of care at low cost. *Beyondblue* is not associated with any pharmaceutical company and we talk about pharmaceuticals generally, but we are also very interested around the cognitive therapies. We believe these are the real treatments for a person's recovery. Through our lobbying, once

again with our partners at the Mental Health Council, we had funding through the better outcomes in mental health project, to have in rural Victoria some clinical psychologists working in General Practices. Those results have been quite spectacular on the data to date. As you may appreciate, the APS (Australian Psychological Society) recommends around $150.00 an hour for a consult. To be fair you can get consults for $90 - $100 from quite a few people, but that's still beyond the reach of a whole range of people who need the service. The services in the GP's practices were $5 an hour. So it was very affordable, very accessible and the results are good. We'd hope in this election year that they might like to loosen a few more dollars up for the continuation of this project. We are very strong believers in mutual self help and support groups and other non-professional agencies. I'll speak in a moment about *blueVoices,* our consumer and carer support and advocacy group, but we also work with other groups. There are some incredibly fine groups around this country, some that spring to mind immediately are the Mental Health Association and the Mood Disorders Association of South Australia, who really do magnificent work and receive basically nothing in funding for the work that they do.

BlueVoices is a national association. We're represented strongly, although we do not have a lot of members in Tasmania. (Just as a matter of interest, never get mentally ill in Tasmania. This is not a good place to be if you're mentally ill). We aim to promote the interest of persons with depression, anxiety and other related disorders, and their families and supporters. Our key aim is to give voice to consumers and carers. Whilst I'm the coordinator of the project, any presentations around *blueVoices* are done by Ingrid or some of our other colleagues from *blueVoices.* We influence, or try to influence and have had a fair degree of success, national policy and community education. We are represented on the Mental Health Council, which is the peak body for mental health in this country, very ably by our chairperson Ingrid. They're the policies that you need to be engaged in. We firmly believe that advocacy is about getting the politicians to open their eyes to depression and we have been quite successful in conjunction with other groups, especially the Mental Health Council. I'd have to stress that we are not in competition with existing groups. We have had the odd bit if criticism around the country, that we set up a whole different group. We set up a group to give people voice who didn't have one and we would argue that we've been very successful to that end. We have a number of reference groups for example, our PND group - the *beyond baby blues* group, which was very ably chaired by Lara Bishop for the first two and a bit years of its life. I've worked with the postnatal depression program, which *beyondblue* funded. Lara and her group have produced a lot of literature. Lara has now handed the Chair over to another consumer member of our group, and we are very pleased with how that particular group is progressing. We're in

the early stages of forming a bi-polar disorder group called *bright blue voices* (this is a name given by the group members themselves). We are very interested and want to be actively involved in advocacy around bi-polar disorder, which is now starting to get a bit more press, but is certainly still a very misunderstood illness.
We have a research group the *blue boffins*, chaired by tonight's chairperson, Kathy Griffiths. Once again, a group that meets to look at consumer based research, because our focus is involvement of consumers and carers for better treatment, better programs and advocacy.

We have a youth specific group called *youth crew*, which has their first meeting this Sunday and we have been amazed by the number of young people around the country who want to share their experiences and engage with us, with the work we are doing. We have a group for older persons called *maturity blues*. This group is incredibly under represented in any advocacy. There was a research study in June of last year, by Professor John Snowdon of Sydney University and Richard Fleming of the Hammond Healthcare group which demonstrated 72% of people who live in residential or supported care, over the age of 65, have significant psychological distress. It's a very significant number and we are committed to working with this group of people, to try and change some of that around by research and program implementation. We will have a group based on the needs of persons living with anxiety and as I said earlier, Nicole and I are just starting that research now. We have done 8 or 9 groups around that and we want to get some more data before we start engaging with people to form an advocacy group. *Beyondblue* have financially supported the team, and assisted us in everything we do. I have been involved in advocacy probably for the last twenty years, and I've never had the opportunity to work with a group where certainly, Ian Hickie and Leonie Young, our current CEO, have been very gracious and supportive with finances and really putting no limits around the work that we are attempting to do.

Question from Audience:
Excuse me have you done any thing with schizophrenia?

Bernard:
We are not involved with schizophrenia. We are funded, very specifically, by the various funding bodies for anxiety disorders and depressive disorders. Schizophrenia certainly needs a lot more research and advocacy but there are some particularly good groups, for example The Mental Health Council of Australia and the Mental Illness Fellowship of Australia, which focus around schizophrenia. The Mental Illness Fellowship particularly. We would like to broaden our base but in fact we are not allowed to by the constraints of our funding model.

Question:

So schizophrenia is not a depressive disorder?

Bernard:

People with schizophrenia certainly are depressed and there are very strong co-morbidities around depression and schizophrenia, however we are not able to focus on the schizophrenia side of the illness predominately. We have had people in our groups, and work with people who have schizophrenia with a co-morbidity of depressive disorder.

So, we've tried to promote wherever possible the 'lived' experience as we talk about. We've engaged with some high profile people. Gary MacDonald, a famous Australian actor is a board member of *beyondblue* and has done some wonderful work in awareness raising around the country. We've done a lot of presentations, tonight it is Nicole and I's turn, but our other colleagues have done a significant amount of presentation about their work. We've had a number of stories in the media around the personal experiences. Publications, our work and that of other researchers, are published broadly in journals and books. A very good book came out last year – *Depression – out of the shadows* which Ian Hickie wrote. Ingrid has been engaged to write her autobiography as a person living with mental illness. We are involved in promotion through the arts. Last year in Melbourne and Sydney, and recently at the bi-polar disorder international conference in Sydney, a play called Dr Cade was presented by *beyondblue*. We paid quite a large amount of money to have it. It was written by Neil Cole, a person who lives with bi-polar disorder and it was the story of John Cade, the Australian psychiatrist who discovered Lithium. It was a three-person play and a particularly memorable and moving piece of theatre which has played to about 10,000 people to date. So it's really got the message out there in a powerful way. I'll hand back to Nicole now to speak about bi-polar disorder form the lived experience of consumers.

Nicole

Ok, this is a separate round of research that we've done, really looking at the lived experience of people living with bi-polar disorder, formerly known as manic depression. There were a lot of similar themes that came up in relation to the general depression data that I showed earlier. But there were also a number of very unique factors that came up as well. I've left out the front a number of fliers, this is just a research summary, an update of the latest finding in relation to bi-polar disorder so that you can have access to those.

Certainly when it comes to the issue of bi-polar disorder, the issue of diagnosis and identifying that something was wrong in the person (because again we used the same questions) is really a hit and miss thing whether someone is diagnosed accurately with bi-polar disorder. And we found that the reason for that was because there were a number of barriers to recognising that a person might have bi-polar disorder. First of all with depression a person might be completely well and then develop an episode of depression and they may then recover as well. Whereas in the case of bi-polar disorder or manic depression people are living with their illness on an ongoing basis and it's all about coming to terms with and managing their illness. But a lot of people talked about when they first came to recognise they might be suffering from bi-polar disorder.

"It was such a gradual progress. It had sort of been there in the background all the time, so it made it very hard to identify a sudden change in the way things were. It made it harder to detect".

"Mental illness has been such a normal part of my life that I didn't know that there was something wrong until I became an adult".

A lot of the time the experiences of bi-polar disorder were put down to just adolescence, just a phase of growing up and hoping that it would pass.

"Mine started in teenage years as well. Round about the 14-15 mark. Same thing - being suicidal, withdrawn, isolated, hating the world, thinking everyone hated me. I had voices but I never thought anything of it".

There were also obviously unusual personality traits that some people might have displayed as a part of the illness, but these were again just put down to personality.

"There were often times when my school friends or strangers would think, "You are so high, what are you on? You can't be normally happy, you cannot be! I find that really difficult because I can't remember any difference. It was always this way".

So one person might have very high periods during a manic phase, or very low periods of depression. People just thought that that was their personality and not consider, 'well this is unusual behaviour, and maybe it's a sign of an illness.'
Others describe being unsure.

"At 16 I knew that something was amiss but I wasn't quite sure what it was. I was very distant from what they [my friends] were doing".

As a result of these different symptoms, over time, people often became very disconnected from their support groups or family members. And that in addition with experiencing more severe symptoms often led to even greater social alienation.

"How id I know that I was sick? I knew I was sick I suppose when I realised that people didn't want to be around me and I had these things that I believed entirely to be true".

So having dysfunctional thinking, and having people isolate them as a result, gave them the idea that there was something wrong with them. People often describe turning to the use of drug and alcohol, not only to treat the symptoms but also to combat the isolation.

"In my teenage years I sort of knew, I was always up and down, I cracked it, lots of breaking things, way too much energy at times. Eventually I discovered alcohol and I thought I'd use that. It was a way out".

Others knew that there was something wrong but it wasn't actually until the incident of crisis that they actually got the right help and got a proper assessment, and then got a diagnosis.

"I just decided one day to stop trucks. I stood in front of them. It wasn't as if I had joined a protest, I started the protest. I parked the car and said, "stop". That brought me to the attention of the police and they took me to hospital".

So this is obviously where the illness has progressed for some time and it's not until something quite chaotic or a crisis occurs that the person actually gets any sort of help.

We know from other literature that the diagnosis of bi-polar disorder often takes a long time, and there is frequently misdiagnosis. But with this research, being exploratory and qualitative, we can actually try and understand why that was the case. And we found that the lack of understanding in the community in the first place, and the isolation which I have just described, would actually prevent people from getting support or getting other people to identify that maybe there is something wrong. As a result it would take a long time to present to get help and then hence get a diagnosis. To compound that even more people were often misdiagnosed by

primary and secondary health professionals. A report came out, I think it was last year, by SANE, which looked at people who had often received 4, 5 or even 6 diagnosis before they got the correct one. In the meantime these people were often treated with other illnesses.

“I was first diagnosed as being borderline psychotic, then I think schizophrenia, then I was bi-polar and a little while ago my psychiatrist thought I had schizo-effective disorder. But I have since been re diagnosed and I have got bi-polar disorder”.

Imagine being re-diagnosed with so many physical health conditions! The lack of awareness is so great, not only in the community but amongst health professionals as well, leading to constant misdiagnosis and the wrong treatment being delivered. So, we saw the absence of intervention, in some cases. Inappropriate treatment, and of course if the person is not being treated adequately it increases the risk of hospitalisation after a crisis event.

“I was regarded as schizophrenic. For some reason they decided, “no he’s not schizophrenic”, and we’ve been giving him the wrong medication for the last 29 years. That’s why he is having relapses even though he takes his medication”.

That was all around the issues of detection and diagnosis and the impact of that on the person. The second part of the research I want to discuss is what it is like/the impact of living with this sort of disorder on a day-by-day basis. It is one loss after another. A person’s life really becomes deconstructed almost, as a result of living with untreated and unmanaged illness. In particular people would talk about their phases when they would be going through a manic episode or were particularly high. They would describe the guilt and shame and embarrassment they experienced when they had recovered from one of these periods. The things they might have said or done and how difficult it was to live with and face people as a result. Because of the lack of understanding, often those behaviours weren’t recognised as part of the illness, they were just seen as the person being a bit weird.

“If I did something too outrageous in one town, I would just pack my bags and move and go on and go somewhere else”.

People also talked about the financial implication when having a manic episode. For example, going out, excessive spending on the credit card, getting themselves into severe financial debt.

“When you have mania you become financially broke, or you end up on a pension”.

Often people would be called to the attention of police as a result of getting themselves into a crisis situation. And the way that this is dealt with by the emergency services was often described as being very frightening and dehumanising.

"I'd go downstairs and there were two police officers in the front of the stairs and it took my breath away".

"I have had one experience with police and I never want to see them again".

With physical health, if you had a crisis you'd get an ambulance because that poor persons unwell and they need attention. With these situations the person often gets a police van and this only promotes the stigma and increases the shame and humiliation that these people can feel when they are so unwell. As a result, a lot of people described the fact that because of the manic episodes they might have ended up with a criminal record.
"I have got a record from an episode also. I was drink driving and breached a restraining order. They're there for life".

So it really has long-term implications for the person, particularly in relation to getting work. People talked about the significant strain of living with the illness and young people in particular talked about things that they would engage in causing quite disastrous consequences.

"I was still so ill, and I mean manically ill which is a dangerous sort of thing, and it was very destructive to our family. It has taken us til now to resolve those disgusting things that happened. It takes everyone a long time to recover. You're talking three years there."

When parents are living with manic depressional bi-polar illness, they actually describe the fact that young children were a lot more accepting than older people in the family or parents were of the illness. But unfortunately because of the nature of the illness, these people talk about sometimes having their children actually removed from their care because they were deemed inadequate to be able to look after them.

"And I kind of said 'well I've looked after the children twenty-four seven through some really extremely stressful times with having a mental illness'. And they have said 'sorry, you're not a fit parent' basically. This is what the courts told me and I lost custody of my two children. That was a really difficult time for me".

As a result a lot of people have to go to great lengths to get their children back in their care. This is often, in some cases, having to prove that they can live without their medication and this can be of course to the detriment of their own mental health.

"I have a great psychiatrist and a great GP, but I can't use them in the way that I would like to, because they have to do a psych report on me for the hospital for court to say that I'm well. To say that I'm compliant, that I'm good, when in actual fact I'm not. He tried to talk me into going back on antidepressants or mood stabilisers and I said 'no, I can't be on this medication because that's just reinforcing to the court system that I really cannot handle my illness. I cannot be a parent'. So it has been really difficult for me to deal with these things. You get to the point where you've had enough".

So it would be about as ludicrous as telling a person who had diabetes that they couldn't take their insulin, that they had to prove that they could survive without their insulin. Which is just ridiculous, but this is the case - the lack of understanding and the way it can reflect on how the courts look at mental illnesses. People also talked about the profound effect that the illness had on their relationships with their spouse or partners. They talked about the highs during manic episodes, which might lead to increases sexual promiscuity, increased drug and alcohol abuse and increased high-risk behaviours. So that's one extreme, and then on the other side, they have extreme lows where there's extreme depression and withdrawal.

"Being manic there was sexual promiscuity. I had an affair with another patient. It's pretty damaging to the marriage"

"And that's not unusual for women to get themselves into pretty hot water in that regard when they're manic. In fact I think I entered marriages in manic states and left marriages in manic states. More than once actually".

So there is an impact on relationships, we know that there are high rates of divorce and separation. But this really explains why and what it is about the illness, and it's treatment in society that might actually lead to such disastrous statistics. As a result we've found a lot of these relationships ended in divorce.

"It was a great trial to my husband all the way through and he finally got jack of it and left. And that was well before I was diagnosed, that was nearly twenty years before I was diagnosed".

So all this time the person doesn't even have a diagnosis to be able to explain, or a context to put to all the behaviour. It's just put down to the individual being extremist or having personality issues. So there's not even a context and without any context or illness there can be no treatment. People talked about the impact of the illness on their friendships. They were extremely isolated from their social support networks and as a result had to turn to support groups, which would be their only support.

"Before I came to the notice of the authorities, I had destroyed half a dozen friendships".

"*In the end we just end up mixing with mental illness because there isn't anyone else left in your life*"

Family is again isolated because of the lack of understanding and the impact of stigma.

"I never got visits in hospital from any of my family. It was quite interesting because my cousin had an engagement party and I was the only relative not invited"

Health professionals also contribute to stigma.

"I think that the profession that supposedly helps us stigmatises us too. Really badly. When you are in hospital and you are ill you are not treated as an individual, you are treated as bi-polar. I think that what leads to that attitude in the mental health profession is that they only see us at our worst, so to speak. They don't see me now" (This is someone when they are well).

Also of course, the impact of discrimination in the workplace from stigma extends to bi-polar.

"I'm looking for work at the moment. I got a job last week and I told them that I had bi-polar disorder and they didn't want me. It's hard if you tell them".

"I was full time and then I was made part time and their excuse was that there was not enough work and the government funding didn't come through. I will never disclose again, because even when I shouldn't be stigmatised I am"

Just in relation to the impact on family,

"When I got out of hospital I lived in a hostel for eighteen months and had no one to vist me. I was destitute in the hostel. And you quickly become homeless as a result of these illnesses"

So as you can see the impact of all these different areas of a person's life really starts to deconstruct the core vital elements of a person's existence.

"I came from an environment where my life was very affluent and then to have my children taken away and to be in a housing commission house and to be on a pension and not having any support. Through the illness I lost my children, I lost my home. I lost a lot of my friends and all of my self-esteem and all my confidence".

So really a person is eroded away because of the illness and because of it's mistreatment.
I'm going to hand back over to Bernard now for the final part of the show, who will talk about these people's experiences, particularly around accessing treatments.

Bernard
As we've spoken about tonight, there's certainly very poor detection and diagnosis with people going for ten to fifteen years without it. There is ineffective management of these illnesses.

"My GP diagnosed me with chronic asthma, I was actually having a nervous breakdown".

"I had an episode eighteen months ago and I dropped one tablet out of my regime on the advice of the GP. I have had hospitalisations in two months because of that".

There is a limited scope. It is very much around the medication focus. You are probably aware of the figures that suggest that only 62% of people with a mental health problem actually present for treatment. Of those 62% around 75% see their GP's, but the really outstanding and disturbing figure is that only 15% of people get an evidence-based treatment. Whether that's a cognitive behaviour treatment or even a medication. So there is a lot of work that needs to be done on educating health care professionals around the treatment that needs to be done.

"Every GP I've dealt with pretty much, it's just a script writing exercise, that's all".

"I went to the GP, which is what I was told to do. I said "look I really think I'm depressed. He didn't ask me one single question".

You may be aware of the statistics, before the better outcomes in mental health project that said the average GP consultation for depression was 7 minutes and the average consultation for back pain was 11 minutes. That's not suggesting back pain is over treated but I think it does indicate dramatically mental health problems are vastly under treated. There are long waiting lists

"By the time I could get the appointment I never needed the appointment, so I was never sure what I was doing there and so it would end up being a pointless exercise. Talking about everything I did, I could do that with my friends".

Hospitalisation – I need to make a comment around the treatment with healthcare professional because what came through profoundly from so many of the people we spoke to is that the visit to the health care professional was in fact a dehumanising experience.
"There was not one question based around "how are you feeling today?" This must be a terrible, hurtful, painful experience for you. It was almost a checklist of symptoms rather than any human interaction"

And certainly if we can achieve even better assessment through the General Practice model we'll have done something worthwhile. Because if people can't be engaged with the caregiver, then the treatments don't matter because they are not getting the treatments. Hospitalisation - it can be very difficult to be admitted. There are either no beds or else you're made an involuntary patient. In fact it's almost a matter of discharging the least ill person from hospital, rather than the person who is best able to be discharged because they're well again.

"I always come out of hospital feeling resentment and a lot of remorse".

"I don't go to hospital anymore. I don't feel comfortable. I don't trust the system. The system has failed me miserably".

The mix of people in health units can be quite disturbing and quite distressing. We've had some younger people say how scared they are when they go into hospital to be put in the same locked unit as somebody who is in the throes of a chronic schizophrenia episode, or in the throes of a manic episode. And this person happens to be depressed. It's a very intimidating environment for people to be in. There is certainly a promotion of stigma. There seems to be an undermining of the patient, a lack of respect for the human quality that people have. And if you can't engage with your health care professional to talk about the issues that are important it is going to really impede any sort of recovery at all.

‘Everytime I’ve got to see the senior specialist at the hospital for something, I get so churned up and so really scared of it, because I think that they are going to judge me. They are going to think it is all in your head. You’ve got to push for your own health care”.

There’s also the discontinuity of care. I am sure we’re all aware of how quickly registrars and interns change their rotation in the public health care system and as a result continuity of care is not there. One of the huge frustrations people experience is repeating their story every six months when the rotation takes place. There’s really a lack of case management and there is a tremendous onus placed on carers, yet we’ve got the same group of healthcare professionals who say due to confidentiality I can’t tell you things. I am sure it doesn’t take a rocket scientist to argue that if you are caring for somebody, you need information. In fact there is very solid literature that if the carer is engaged from the very outset (with the permission of the consumer) then in fact the bounds of confidentiality are not the same as has been argued by so many people. Consumers and carers must argue for their rights. If you want to be involved, or if you are a carer and the person wants you to be involved, you tell the healthcare professional. It is your right. Exercise your right…

Tape changed over – short piece missing

…so the maximum you’d ever see the same person would be twice. You just get told to tell your story, which is what they want. They never look at the file before you get there.

Imagine if we each had to tell our own story about diabetes, epilepsy or anything else every six months to someone different.

The crisis assessments and treatments team are often not available. Or if you’re out of area, that areaisation issue becomes quite an impediment to care. When a number of consumers have spoken to us about filling a dual role, of a consumer and a carer, they ring up the crisis team for some help and have a lack of credibility issue. The crisis team will ask them “is this really happening, are you sure this happening”. The story that comes to mind is a person who was in one of our groups in Sydney, who suffers a bi-polar disorder. She was describing her daughter, who also has a bi-polar disorder, on the roof of the garage wanting to jump off, and the argument this person was having (who was quite well at the time) with the crisis team to come along for assistance. Sadly the girl jumped off and broke her leg.

"Well now you just get told it doesn't sound life threatening, we're not coming and yet who on earth in any family would be ringing up a crisis assessment team unless it was life threatening".

"You don't ring cat teams in a crisis, you ring the cops and the ambulance, because if you ring the cat team they think you're well enough to ring us so we're not going to come out to you".

"What medication are you on tonight. What are you doing tonight? See you later"

These are not figments of our imagination; these are direct quotes from people we've worked with.

Now, a little bit about the virtual network, because what we are trying to do with this work that we're gathering is to educate health care professionals. The more we publish, the more we talk, hopefully the more impact we'll have on changing some attitudes. The more consumers and carers not only ask for their rights, but demand it, the better our health system will be. I'll briefly finish on the virtual network and our website, which has got a lot of information, and by the end of this month will be significantly rewritten. The address is *www.beyondblue.org.au* Please have a look at it. There's some very good information, some excellent consumer and carer stories and ways to be involved. The virtual network is our email service. We currently have over 8000 names, all around Australia and right around the world from the work we do. We regularly send emails with articles, references, and more and more we've been engaged with groups like the University here, as well as the Mind and Brain Institute in Sydney, doing research projects through consumer based research. We're actively engaged in advocacy through the virtual network, through letter writing campaigns and visits to politicians, and I've just mentioned the research that we do. The mission of *beyondblue* and *blueVoices* is to reduce the prevalence, risk and impact of depressive disorders within the Australian community. If we can raise the awareness on these so called high prevalence disorder successfully, we believe it will roll through onto the, very serious but numerically not as high, issues around schizophrenia, personality disorder and the other major mental health issues of our day. I now look back and laugh quite significantly. I remember when I was a student being told that if you didn't have schizophrenia you were part of the 'great worried well'. At *beyondblue,* we try to open our eyes to depression. Anyone who thinks these illnesses are about the 'worried well' not only has blinkers on but they have both eyes burnt closed. We as a society can change a lot. We do a little bit but as a group we can do an awful lot. Hopefully tonight you have heard some stories that may have impressed or distressed equally. But take these beyond the walls of this

meeting and demand the rights that you are entitled to as a healthcare consumer, or as the carer of somebody. You have rights. Don't let anyone not give you the rights, because then you're not giving yourself the grace that you need to have

Thank you so much

For more information see www.beyondblue.org.au