

## 8. INTERVIEWS WITH CARERS

### The Effects of 'Mental Illness' on Carers and Their Families

The carers interviewed reported a diverse range of experiences. These were shaped by factors such as the nature of the pre-existing relationship between carers and their 'dependant' relative, the nature and severity of the mental health problem in question, and the particular circumstances and resources of the carers, the wider family unit, and those being cared for. Although many carers referred to a strong sense of responsibility, this was often accompanied by the expression of complex feelings about their roles as carers. Some appeared to accept their role with resignation; "One has to accept it...simply to accept it." while others expressed incredulity; "I often think, why do I have such a big cross to bear? Is God punishing me for something?", or frustration or resentment about their situation; "I want to break free of this psychological prison."

A theme that was evident across the interviews was the profound impact that being a carer has on the daily lives and opportunities of both carers and their families. Accounts of compromise, resignation, and frustration were common. Carers often reported that their work and leisure pursuits, freedom of movement, and use of time had been severely curtailed as a result of their need to offer constant care and support. Some carers had to stop working to undertake care, and were subsequently struggling with bills and making ends meet. There were reports of feeling isolated, and accounts of conflict between carers, and other family members. Major disruptions to life plans were also common. Amongst the difficulties reported by carers were the unpredictable or distressing behaviour of their relative, their need for constant observation and monitoring, and the possibility of verbal or physical violence, and suicide.

Many carers expressed conflicting emotions as they described the radical changes in life circumstances that came with the mental health problems of their relative. The following carer married her partner late in life, before he became ill, and within a few years found herself in the role of carer:

*How does this [the mental illness] affect you?*

It frustrates me, because he was quite different before he had this big operation. After the operation his memory got quite a lot worse. It was a big step downwards. For the first six months he was in a state of semi-consciousness. He slept twelve hours out of twenty four. Gradually, when I kept coaxing him to eat more and walk more he got his physical condition back to normal but he never returned to the mental condition he had before. People tire him a lot, he can't carry on a conversation with anybody, and even television wears him out. He doesn't look at television much. His memory for everyday things is practically non-existent. He does not remember that he should change his shirt, underpants or other clothes, or that he should have a bath. He belongs to the library and borrows books. I go with him, because he has a problem with walking - he often trips and falls if someone does not hold him. Sometimes our neighbour gives him a lift in a car when he wants to go to the library. The books he borrows are usually on psychological topics, but he does not remember much of what he reads... Looking after my husband is a big responsibility. Sometimes I feel quite tied to him. In January I wanted to go to Sydney for two weeks to visit my cousin. I ordered Meals on Wheels, and when I came back, out of 14 meals I found 4 in the fridge. Twice a day my friend came and she tried to coax him to eat. She used to pull things out of drawers so my husband could put them on. He used to do that, but he would forget to bathe. I wanted him to be clean. When I came back I washed all the clothes he changed. Because he is my husband, a person dear to me, things are not that difficult. But they are not that easy either...The situation is

frustrating. Sometimes I feel depressed. When he is asleep I sometimes have a good cry, but generally I accept this as part of living....He was a highly educated man with impeccable manners, but he changed a lot after the operation. The doctor told me after some time that he has dementia and it would be hard to expect him to be how he was before. I have some nursing education, because I went to nursing school in Poland, so the physical side of his condition was not a problem for me. But his mental condition depresses me.

- Polish carer

Another carer indicated that although she 'felt sorry for her husband', her life had changed too, and she 'no longer had any life of her own':

*How does this illness affect you and the rest of the family?*

It has a very negative effect. I feel very sorry for my husband, because his life has been ruined, but I also have to put up with his bad moods and loss of memory. My life has changed too. My life now revolves around looking after my husband. I don't have any life of my own. I organise the entertainment for him, look after his physical needs, prepare food for him, clean the house so that he has pleasant surroundings and so on. For example, in the morning he listens to music, then he has a number of television programs that he watches. In the afternoon he has a nap. Sometimes someone comes to visit us. There are some videos that we watch together. He also goes to therapy once a week, and everyday someone comes to bathe him. That is how our time goes. When the weather is good we sit outside. I often work in the garden and my husband watches me. At the beginning he used to go to speech therapy as well, but now they have stopped taking him. He speaks but little. Sometimes he says a few words and I have to guess what he wants to say.

- Polish carer

Carers talked about the constant worry, and overwhelming responsibilities involved in caring:

As far as I am concerned I have huge responsibilities. I have to think about each day. In the morning I have to take my son to school. My daughter goes by bus - she is fine for now. But what will happen with her I don't know. I have to be realistic in what work I can do...I am occupied, I am always doing something. But this work is the sort of work which revolves around worry - always some sort of worry.

- Bosnian carer

It [The mental illness] affected me a lot. I had my own problems, you know, with my husband. You know, you have your own problems, then you have to cope with someone else's...

- Polish carer

## **Changes in Family Dynamics**

Many carers described their difficulties with the change in the identity of their family member to that of a 'mentally ill person'. The consequent change in family dynamics, in many cases, led to considerable pressures on pre-existing relationships, and even thoughts about separation and divorce:

I just sometimes can't believe that this is really D. That this is him.

*Like he is someone else?*

Yes.

*It must be very difficult for you.*

Yes. I sometimes think, "Really, I will divorce him." Sometimes I say it. I don't know. So many

times I have to keep quiet. He always wants to be in the right.

*What was it like before?*

Well I guess everyone thinks their marriage is the best. But even the neighbours used to say it. How beautifully we lived, how we got on, how you'd never hear a bad word from our home, how good the kids were, how good they were at school. I think.... we never had any problems. See, we have been together for 24 years. He had never laid a hand on me. Sometimes, now, I flee from our home.

*Has he become aggressive?*

Yes. When we go shopping, whenever I want to buy something he says, "No! don't get that. That's no good." He always wants to buy what he wants. So most times I just keep quiet. I keep thinking it will pass. Next time we may buy something I want.

*So you have the burden of keeping the peace in the house? But it must be difficult for you?*

Yes, yes. He loves visitors. But when people visit, when we have many visitors, he always says... he always yells at me. He always says, "It is your fault." And I say, "Come on and help me sometimes when our daughter isn't here." He always says, "You have to do it all." I mean...

*Was it like that before? Did he help you before?*

Before, ...he never allowed me to cook a meal for the next day. He worked two days in the first shift, two in the second and two in the third. And I worked non-stop first shift. So he never allowed me to cook the meal for the next day. He'd say, "Why should you cook the meal for tomorrow, we'll have it fresh, I'll cook it." So it is difficult for me to comprehend now that this is him...

- Bosnian carer

The effect on some families has been profound. A number of carers reported distress and fear among their children, episodes of verbal abuse, physical threats and assaults, financial burdens, and disruptions to sleeping patterns:

*You've been married for almost twenty years, do you believe that your wife's illness has affected your whole family, and if so how much?*

Yes. The most profound effect was upon the children, the effects were not so great upon the older and more mature. I, myself, have some experience in this matter. When my children were young they did not really have much to be concerned about when their mother came under the effects of her illness.

*They thought it was but a common illness which did not call for any concern, is that right?*

Yes, because her illness would come and go quite often. However when they grew up they noticed that their mother's behaviour was unlike a normal person's. They were most concerned about their mother at that stage.

What was their reaction to their discovery of their mother having this illness?

My daughter's reaction was the most profound, as she was so shocked that she was afraid to talk to her mother. She did not understand why her mother behaved like she did. She had lots of stress to deal with, she wondered in fear, "Will I become like her?"

- Chinese carer

This quote has been included here in order to illustrate the effects that caring for a relation with a 'mental illness' can have on families and children. However, there are a number of other issues raised by this carer's account. As will be discussed in a later section, the stigma that often accompanies mental illness may greatly affect the likelihood of carers seeking help from either support services, or from members of their extended family or community. From this carer's account, it appears evident that stigma may also play a role in the dynamics of the immediate family of the 'mentally ill' person. Note the carer's statement that, until they were 'grown up', and were made aware of the mental illness of their mother, the carer's children did not consider the behaviour of their mother to be frightening, or out of the ordinary. Once they were made aware of the presence of a 'mental illness', however, family relations are described as being fearful and strained, and issues of genetic susceptibility are raised; "My daughter ... wondered in fear, 'will I become like her?'" As was discussed in other sections of this report, "mental illness" may be a particularly undesirable term for Chinese communities, as few acceptable corollaries exist in Chinese languages.

She beat the kids and maltreated them. When she gets an attack of these nerves she simply...when the nerves take hold of her she begins to shake, and to yell and scream. She has no control over what she says. She just attacks. And when that happens she goes and takes a tablet...

*Okay, how does her illness affect the family? You and the children?*

Very badly...very badly...When we get up in the morning I make the coffee and we drink it. And when I look at her and smile, she simply cuts me in half. Her eyes seize up and her lips go pale. That is shocking to see...she notices nothing. When this comes over her she seems to drift away. She stands and simply stares at something and doesn't move...

*Do the children notice that something is wrong with her?*

Yes, the children notice. The youngest one, she is only six years old, she doesn't realise. But the two older ones have said themselves that something is not right with her, that she is a sick person.

- Bosnian carer

We [a friend of the family and carer, and the family] all started to be afraid of him...She [his wife] was worn out by his disease. I don't know how he treated the older child, but I know that he was abusing the younger one. So, that the younger child, he himself wanted to run away from the father. So it was also, probably, the reason that the mother took the kids and went away...

*And what effect did it have on you or your family?*

Great... At the beginning, we were all great friends. They used to visit us, we had [a] well developed social life in this region. Yes. In the moment when he started harming the children, started chasing the children, verbally abusing our children like he did with his own kids, always telling them off. He was... strangling a friend of mine, in the presence of my children and my family. We had to call for help, since no one was in a condition to separate her from such a big man. It came to the stage that when he had an attack we were locking ourselves inside our homes. All the doors had to be locked, all the windows had to be locked...

- Polish carer

*Now that your wife has recovered from her illness somewhat, do you have more time to yourself to do other things?*

Yes, I have time to myself at night and I use it to read the newspaper. However, I dare not read too late as I will be too tired if I sleep too late. My wife turns the music up really high...before I wake up so that [I] can't sleep... She gets up around four or five. The children

tell her not to make so much noise so that I may rest longer but she does not listen....She doesn't care that everyone else has to sleep late.

- Chinese carer

## Frustration and 'Feeling Trapped'

A number of respondents expressed frustration with their situation and feelings of being 'trapped'. In one case, involving a Chinese family, the carer reported being at his wit's end, and as having been the subject of his ill wife's "constant interference", and "frequent tantrums and scolding". This carer frankly admitted having threatened his wife, and expressed a desire to have "nothing to do with her". However, he notes, that 'his culture would not allow him to leave'. He asserts that there is no chance of his wife getting better, and that it would be difficult to change his situation and begin a new life. The following gives some flavour of his 'frustration':

*During this time [your early period in Perth] what was the most painful and traumatising experience you had?*

In the past when you cooked her something she would refuse to eat it, saying it was bad tasting, sometimes she would have tantrums and scold you. I often have to put up with her. When I can no longer put up with her I say that I will beat her to death. I have lots of pain and suffering to put up with.

*Can you repeat what you say to her when you can no longer put up with her?*

I say that I will beat her to death. She gives me too much grief. I have no other ideas. In actual fact I have never beaten her. Sometimes she says that she will call the police or say that she wishes to speak with you. When her illness takes effect it gets very serious, she does not scold outsiders, only family members. She does not scold her eldest son.

*She scolds you the most then?*

Yes, me the most.

*Thus, sometimes it is hard to put up with.*

Yes. She does not scold our eldest son, so she resorts to scolding me. She calls me a village man, a low life.

*Village man, low life?*

Yes, I grew up on a farm. In other words I am a village man, a peasant. But I've grown accustomed to it over the ten odd years. However, sometimes I want to break free of this psychological prison, but she has a mental illness and I have to care for her...

*So it would be nice if your wife settled down a bit. What are your hopes and aspirations for yourself?*

I have not yet thought about myself, I only pray that I can afford a good education for my two children because my own English and education is not that good. To be able to give my children a good education is my life's dream. If I ever leave my wife I can always find another woman, but a divorce would not be very beneficial to my children. I've thought about moving out to live by myself. However I believe this is not a good idea.

*So you could never do it then?*

Yes, no matter what, looking after my children will always be my responsibility. I would really like to take my two children and leave my wife, I want nothing to do with her, that way I can put

all my heart into raising my children. In truth, I'm confused about it all, I can't leave her but if I don't I have to put up with her. There is a great pressure tearing at my heart and because of this pressure I have withered somewhat.

*Do you still have any feelings for your wife?*

My feelings exist only because of my children. I believe that it is very bad luck for anyone to have to put up with all this pain and turmoil.

*Do you feel very unlucky?*

Yes, but I have no other ideas. We Chinese cannot bring ourselves to do things which would wound a heart and cause it pain and sorrow. We cannot just dump our responsibilities and run off, we Chinese must carry on our traditional thinking... To tell you truthfully, I really don't want this woman, she makes my future very difficult, it will be a hard road. There is no possibility of giving her a sum of money to return to China, as my children would be angry at me.

*Your children obviously hope that their parents will remain by their side.*

Yes. It would be awfully difficult to build up a new family with a new woman.

*However, if your wife would just take her medications properly there is hope that she will get better eventually.*

No, there is no chance of her getting better, even if she keeps on her medication the subject of her lifespan. It is a subject where many questions arise. She is very thin and scrawny right now.

- Chinese carer

This carer's frank account of his frustration raises a number of sobering issues. In the absence of adequate support, it is possible that physical or emotional violence may occur, on the part of carers who are unable to gain support or respite. This is not to excuse such behaviour, or to imply that it is necessarily a feature of this carer's situation. Rather, this is an issue that highlights the crucial role that adequate support services can play in the lives of those with mental health problems, their carers, and their extended family. In the absence of support, it becomes impossible to adjudicate between the presence of a mental illness in one family member, and the effects of threats of physical violence from another. Such situations offer little hope for either party.

## **An Exhausting Duty**

All of the carers interviewed indicated that caring was an exhausting and ongoing duty that consumed enormous resources of time and energy. In the majority of cases, carers reported that there was no one else available to provide assistance. In the following case, the carer describes work outside the home as an opportunity to escape "the gloomy and confusing environment which is my home", and to "recharge" for the sake of their own mental health:

*How have your many years of looking after your wife affected you?*

I feel that it is very energy consuming. Particularly when she is in a bad state. I have to constantly watch over her. The most dangerous times are when she wants to suicide. My conscience nags at me when I am working as I know that she constantly has the notion to kill herself. It is most complicated.

*Although there is some one to look after her when you are working, do you feel uneasy about it when you go to work?*

Yes, but then again sometimes there is no one to look after her. During those times I feel even more uneasy. Relatives can't always be there for you, they too have things to do and so I mostly have to rely on myself, and sometimes I have to take risks.

*Are you the driving force of your family?*

Yes, if anything happened to me, because my wife has the potential to do the unexpected, my family would most likely collapse. That is, if I am not there then who will run the family? My children aren't yet mature and so the family could not continue if anything was to happen to me.

*How do you feel with all the stress and the responsibility you have to deal with?*

The more my wife is ill the more I look forward to going back to work.

*You'd rather go to work?*

Yes, my job allows me to get away from the environment and to recharge. So that when I go home I have the energy to deal with it. If I don't go to work I too would collapse.

*You too would collapse?*

Yes, I too would collapse. This is my personal experience, and so the more ill she is the more I want to go to work. You can say that I hide from the truth, but to me it is necessary.

*It's like a way out?*

Yes, for the sake of my mental health I have to get away. My job makes me feel good. I feel happier if I can go to work. When I return home I feel much fresher. Working should be a very taxing thing but to me it's not because it gives me the chance to release the tension and recharge and to get away from this dreary and sad environment. When I return I have the energy to care for my wife.

*If you could not go to work and always had to stay at home, how would you feel?*

I could not do it, to me work is crucial, I could not survive without it. It's not easy to deal with people with a mental illness, particularly if the victim is a close relative. You hope for her not to fall ill but she falls ill constantly. Not a few days but weeks and months on end, even as long as half a year, even whole years. When the times are long I feel so exhausted. It makes me very tense indeed. Why is it like this? That's why working makes me feel so good.

*Is working like a form of rest for you?*

Yes, it allows me to recover and to get away from the gloomy and confusing environment which is my home.

*What was the most difficult period for you to handle during your many years of experience with your wife?*

It would have to be the lack of resources to look after her. Even during the most difficult times, if I had enough help it would have been all right. It can be most difficult if there are no helpers, because I have to look after my children and also look after her. Sometimes she has absolutely no notion of what she is doing.

*Is it most difficult when there is no one to help you?*

When there is no one to help me it's like hell. I barely have enough time to cook meals. You can't leave her, because if you do she does all sorts of unusual things. Most important is the

help, the more helpers the easier the problem is to deal with. An illness is inevitable when it is Fate. Nobody wants to have an illness, her having an illness is but Fate's will, I can only trust Fate. It was Fate that brought this upon her. The problem is that one person cannot deal with this sort of environment.

- Chinese carer

Although some carers mentioned that respite care would assist them, by allowing them to go on holidays and the like, as one carer noted, there was no getting around the fact that caring was a twenty-four hour a day job:

*If you did not have any family members to help you look after your wife, would you have any knowledge of outside services and facilities which could help you?*

I know that there is a community psychiatric nurse who can help. The big problem is that she can only come and care for her a short time, she is not able to look after her twenty four hours a day. Like my wife's illness - after she returned home I had a job to tend to and my children were still young, there were meals to cook and clothes to wash. However my wife was still very fragile and she could not handle all the work, and so I was not confident with her being home alone. Even the community psychiatric nurse was insufficient because the government is not able to send someone over for twenty four hours a day. Unless you have lots of relatives here it can be a real hassle.

- Chinese carer

Time is a crucial resource for carers, who frequently expressed a desire for 'time out', either simply for a break or to pursue leisure activities. The only expressed wish of the following carer was that their grandchildren (whom they also cared for) would grow up quickly so that they could have more time to play badminton:

*You say you hope that your wife will listen more to what the family tells her, but what hopes and wishes do you have for yourself?*

I wish that my grandchildren grow up quickly and so don't require me to look after them, so that I may have more time to play badminton without worrying about picking them up from school. If I didn't need to be so concerned with time it would take a lot of pressure off my conscience. I have to get my grandchildren ready for school and prepare them fifteen minutes early, otherwise they complain about me not giving them enough time to get ready.

- Chinese carer

## **Access and Support Services for Carers**

There are a number of barriers faced by carers from culturally and linguistically diverse communities in accessing support services. Foremost amongst these is the lack of knowledge held by carers about the existence of support services; the widespread belief that caring is largely a family responsibility; and previous negative experiences in trying to access support.

For many carers the concept of seeking support for themselves appeared to be so 'foreign' that questions pertaining to this appeared often to have been misheard. When asked whether they received any support, many carers described their relative's support needs. One interviewer commented that it was as if there was a "preconceived idea" among the carers she interviewed that it wasn't reasonable to expect support for themselves when the 'obvious' person in need was the family member they were caring for. However, this may also indicate that these carers would prefer any further support to be extended towards their distressed

relative. In any case, the interviewers often needed to reiterate that the questions related to support were directed towards eliciting the needs of the carers, themselves.

*Have you gone to anyone else for help or aid?*

I certainly have. At the hospital there were the doctors and the nurses and so there were no problems there, however time spent at the hospital can't ever be too long. A person with a mental illness is unlike one with a physical illness and requires long periods of time to recover. The largest problem was after she returned home. She had not fully recovered after she arrived home and so needed more time before she could be fully recovered. This is the time where she needs as much help and care as she can get. I need to go to work myself.

*Is there anyone who can help you?*

She calls upon her family for help most often.

- Chinese carer

Some carers claimed not to have even thought about the possibility of seeking any sort of assistance. Of those carers who were aware that services were available, many had little faith in the ability of these agencies to provide assistance.

*When you had just come to Australia did you ever think if there were any government service which could have helped you?*

No, I never thought about it.

*If you knew about these services would you have contacted them?*

I would have certainly contacted them as I have to look after her from as early as five or six in the morning to very late at night and this is very hard on me. I can only sit around as I didn't know how to buy any newspapers to read or how to do anything else.

*What places do you think could have helped you?*

None.

- Chinese carer

Although the need for socialising - for both people in distress and their carers - came up in several interviews as a valuable form of respite, friends and acquaintances were often reluctant to participate, and tended to "stay away".

*Apart from the doctor was there any outside help from friends?*

In the past, when we were still living in [...], I searched for some friends from the same village in China and friends from the same boat whom also came to Australia.

*Did they help you?*

Very, very little.

I'm not very happy right now, our friends are few and far away though we live in [...] and it is not convenient for my friends to visit as my wife has her mental illness. Last Saturday my wife went out with my two children and when she returned she was in a very happy state of mind, calm and not showing any signs of her illness.

- Chinese carer

In lieu of professional support, or that of friends and acquaintances, help often comes from the immediate family - as in the case of a carer whose husband took care of their situation at home to enable her to look after her distressed sister.

My husband was pretty supportive. He said, "Look, just don't worry as far as the kids go. I'll look after our kids. You go and help her". He couldn't face it, he would get very upset. But he supported me....he sort of took that pressure, even though he was working, looking after my kids so that the times I had to go there, I felt good, comfortable - there was my mum, there was my husband who were looking after my part of the family, while I was trying to help her.

- Croatian carer

When asked whether they would take advantage of respite or other services if they been aware of them, cultural expectations were often described as prohibitive.

I think I would have taken *some* advantage, but not all of it because...you know, I mean, coming from the culture that we come, . . . You know, the culture we have been brought up in, it's very hard. You feel sort of, "Oh, you've got someone else to look after her children, and you're related to her!"

*But what about community, friends, the Church? Was there any support from any of those areas?*

Some of the family friends - yes. But not really.

- Croatian carer

Many carers spoke of their struggle to cope on their own, in the absence of any assistance. Others considered seeking assistance, but reported that their families were reluctant for them to do so. One carer spoke of her situation as 'a personal cross to bear' and expressed limited faith in external forms of support.

I was trying to deal with it on my own. To sort things out with her.

I advised her when we came here (to Australia) that we should see a doctor, so we can see what's wrong with her. She was rejecting that. She didn't want to. She was worried that someone would uncover her illness.

- Bosnian carer

I didn't ask anyone for information. I solved problems in my own way. What I thought was best.

Look, who can help us? I didn't even know where to go to.

- Croatian carer

Nobody can help me. Simply... you can talk with me, but I am living through it alone, do you understand?

And who can help? Who can comfort me?

*Have you ever had any support or assistance from the church?*

No we haven't. No I haven't talked to anyone about it, other than you.

- Bosnian carer

Listen, I talk with the kids and that is all.

- Bosnian carer

Approaching any organisation or any services, means, that they will give you some pamphlets and "you can read them, you can go there, approach them". You go there, and they tell you to go even further. And you walk in a circle, and at the end you decide, that you, on your own, have to take care of it. Isn't it true?

- Polish carer

I haven't tried, because I don't know if I'm entitled to any help or not. They say that if you're healthy then you should work yourself.

*It means then that you have accepted your wife's sickness as a cross you have to bear. Is that it?*

Yes, because I need to look after her. She is a human being and she is sick and I have to accept it.

*Did you ever go to any organisation to seek help?*

No, I did not go anywhere and did not ask anyone for help.

- Polish carer

## Help as a Final Resort

Some carers accepted help only as a last resort.

When I came home after an operation I had, Silver Chain sent me a lady who cleaned for me once a week. My friend used to shop for me and my neighbours used to cook and help me feed my husband. One neighbour is Dutch. She lives six floors above us. Another is Polish and she lives in the same street in her own house. When I was feeling better, my neighbours used to help me with small chores such as shopping, washing etc. and the lady from Silver Chain used to help me with the cleaning.

*How long after the problem started did you start looking for help?*

I did not seek help until I got sick. After I came home from hospital my neighbours helped me and Silver Chain. When I went to Sydney, Meals on Wheels provided the food for my husband and my friend kept an eye on his other needs.

*Did you get help from the church that you attend?*

I go to church here in [...], near [...]. The nuns there are very helpful. They pray for me and my husband. One of them is of Polish descent. When I was not well she used to come and take me to church in her car, so I could be at Mass on Sunday. These sisters are lovely. They gave me a lot of moral support. The sister who is Polish by descent comes to visit me sometimes and gives me moral support. Also my neighbour from six floors higher is very calm and very helpful. I can go out for a few hours and she will come in and warm up my husband's dinner and serve it to him. It is a great help for me. I feel very comfortable in her company, I can practice my English with her and not feel stressed that I make mistakes.

- Polish carer

## Information and Communication Barriers

Although most carers agreed that knowledge about their family member's 'condition' could be empowering, and that the provision of such information is in itself a form of support, the majority of carers reported that such information was rarely offered. Rather, carers had to be pro-active in order to obtain information.

No one ever wanted to help us or explain the situation to us. I must mention here that Dr [name]- only he allowed a bit of extra time and devoted extra care.

- Bosnian carer

This was rendered an even more difficult task for the majority of the carers interviewed, who reported significant difficulties with the English language. The inability of many carers to communicate in English presents a further barrier to accessing support, and may also increase social isolation.

## Stigma

Although no questions about stigma were explicitly posed in the interviews, the issue of stigma pervaded the carers' accounts. The 'secrecy' surrounding 'mental illness' and carers' 'reluctance' to seek help was explained as being in response to the potential stigma that comes with 'having a mental illness in the family'. A number of carers stressed that stigma often extends to encompass entire families.

I would only ask my closest friends for help and they would have to be understanding people. This kind of illness is not any common illness and I'd rather not too many people find out about it. Society associates people with this sort of illness with stigma and this makes me want to keep it a secret even more.

- Chinese carer

Because of the stigma associated with mental illness, families are often concerned about how "having mental illness in the family" would affect their children, were this to become known in the community. Focus group participants also reported that the opportunities of children whose parent(s) have been diagnosed with a mental illness, or are in distress and in need of support, may be profoundly affected.

Everybody...if they knew you had somebody like that in the family, they would insult you, they looked at you as though you were different, they looked at you like you were the same. If they knew your mother had schizophrenia they thought everybody in the family had the same problem.

For mental illness in Croatia and in Bosnia-Herzegovina they...for very ill people...they treat...they look at them like....I don't know, this is very hard to say - like dogs, or something like that. They treat them more like dogs than human beings.

- Croatian carer

Often the stress carers was under was quite evident in the interviews. Some carers were themselves taking medication in order to cope. The following carer described her husband's 'mental illness' as being something that would soon drive away their teenage son, who had become too embarrassed to bring his friends home for fear of how his father might behave.

He is at school now but soon he will move out. I know that he is ashamed. One day if he has a girlfriend.... you understand? And friends. How will his father behave? Understand? I tell you I feel sorry for him (husband) because he is ill ... I went to the doctor and he said to take a tablet to settle my nerves when I feel the need.

- Bosnian carer

## Trust

All interviewers attempted to establish a relationship of trust in advance of any formal discussion. In most cases, this was successful, as many of the interviewers had been recruited on the basis of having well-developed relationships with their respective communities.

Establishing this level of trust appeared to assuage the guilt some carers expressed in talking about the person for whom they were caring. Some mentioned they felt 'somewhat disloyal' when talking about the family member diagnosed with a mental illness - as if it were a betrayal. Others whispered when discussing particularly personal issues. According to a number of the interviewers, 'the carers' need to talk, and to get things off their chests was palpable.'

I used to think "Oh... If I talk to someone and she finds out it might set her back again, and that was always at the back of my mind. But it never happened, because I was very very careful.

*With whom you told?*

Yeah, and I mean...she didn't...one of her problems was that she didn't have many friends, because she didn't trust many people.

*Is that a part of the illness?*

I think so. I think so, yeah.

- Croatian carer

Often carers were resistant to seeking any kind of help due to their 'loyalty' to their relative. This protectiveness appears to be due, in part, to a fear of disapproval from the family member experiencing psychological distress.

No....I wouldn't ask for help because later she would really get at me. You know, "I can't trust you." Because she was very very ashamed. When she was at her best then if she heard something she would get back at me. So I felt that I had to be trustworthy otherwise she might do something, like...

Yeah, he was judgemental. He sort of looked upon it...down at us, like it was our fault. He would even say, "I just wish I had never come into this family", you know. Yeah: "I just wish I'd never met any of you," and things like that.

- Croatian carer

Having access to family networks does not necessarily mean that help will be forthcoming for carers. There is a widespread assumption that people from 'ethnic' communities, as part of their tradition and culture, will feel obliged to care on their own for their family members in need, and that it is seldom culturally appropriate to interfere in these relationships. However, health professionals and support organisation need not continue to impose responsibility solely on carers. Rather, carers need to be informed about the support options available to

them. Many carers recognised, however, that due to the lifestyle migrants are exposed to upon immigration, and the acculturation of the second generation, family dynamics may be changing, and these changes may exert an influence on caring patterns.

One carer spoke about her inability to 'open up' to her extended family. She reported feeling that they were always too busy to be of any support. She described the congregation at her parish as 'Sunday acquaintances' and not people she could turn to for support. Many carers spoke of the need to establish trust over time. However, time is often a luxury that is unavailable for carers.

I like to be independent, but I also like to open my heart...to the family. But when I am sick, I cannot open my heart...to many people. I can hardly find one person that I could open my heart to, I can talk to just, and that's all who can help solve my problem.

They're all really very, very busy. I know that. But I'm upset because I...well I would like to come and see them, but they're always too busy. And also they drive and I don't...It's easier for them to come and see me, because they drive. But still they're...they're overly busy with their families. And things like that. So...Actually we don't have a very good relationship because we don't see each.

I ask you - how can you talk to somebody if you're not that close?

*And your immediate family is in Croatia, are they?*

Yeah, yeah. That's right, yeah.

*What about Church? Have you ever turned to the Church for help?*

No. I can talk to them nicely on Sundays after church, we can have a cup of tea together, we can talk about what we've been doing, and things like that. But about personal things..... I can't talk to them either.

*So it's just a very superficial sort of contact, is it?*

...Ah, it is not superficial, but I can't open my heart and talk to them.

I believe I could even trust them. But they don't want me and I don't know them. You have to know somebody...so you can open up.

Trust also appeared to be a contributing factor to the willingness - or otherwise - of carers to accept in-home help and respite, when available.

I feel very private about my house and I wouldn't like somebody coming to my house and...you know, like doing things for me and things like that....I'd feel it just wasn't right.

*Is that because of the way you've been brought up, that you should do your own stuff? Or is it because you don't like somebody imposing on your privacy?*

Yeah. Both. But it's a good idea otherwise. Because like...somebody passing through our personal things and things like that. It's just...not right.

*But if it was just basic things, like getting the dishes done, and cooking a meal?*

*Would you be able to accept that sort of assistance?*

Ah....Ah...I'm not sure. I'm really not sure.

It's very hard...to trust somebody who you don't even know, and things like that. Walking into your house and doing things...

- Croatian carer

## Talking to Someone Who Understands

Many carers expressed the desire to talk to someone about their worries, fears and experiences of their role in caring for a family member. However, due to the nature of the problem and the ever-present issues of stigma and embarrassment, finding an 'understanding' person to talk to – even in the absence of language barriers - is a challenging task.

But talking itself...when you talk to someone who understands, that is very welcome - to talk it out. But if you talk to someone who later laughs at you - it is funny to him, but to us it is sad.

It is difficult. It is difficult to trust anybody. You can't trust anybody. I can't say to my wife that she doesn't trust anybody because I myself don't trust anybody. I sometimes don't trust myself because of these experiences. I do believe there are people who could help. A good doctor could help. A good person could help.

When you find yourself in this situation and you see how cold everyone is, how coldly one is received - you come home and you think about how you were received.

- Bosnian carer

## Communication Issues

Carers often reported difficulties in communicating with service providers, and that they found it hard to gain access to clear explanations about the 'illness' of their relative. Carers may suffer considerable hardship due to their inability to communicate with medical practitioners and other service providers. Not only can this result in a lack of information about the 'condition' of their relative, carers may be unable to ask specific questions of health professionals, or to make their own support needs heard.

Communication difficulties were described as being 'not just the result' of carers' own inability to communicate in English. Many carers asserted that there was seldom enough time allotted for meaningful consultations, and that this is particularly pronounced when an interpreter is used. Insufficient time for medical consultations was also recognised as a significant problem by the focus groups held with community members, and by the health and mental health practitioners interviewed.

*Have any doctors here told you about the nature of the illness?*

Even the doctors in the hospital did not tell me much about it. They only told me it was a mental illness.

*Did the nurses explain to you the nature of her illness?*

No, because the nurses did not speak Chinese and so I could not really understand them.

*Was there someone to interpret?*

When we visited the doctor there was.

*Did the interpreter explain the illness to you?*

There was an explanation but it was very trivial.

*What did the interpreter tell you about the illness?*

Whatever the doctor said, he translated.

*Did the doctor tell you what sort of illness your wife had?*

No, the doctor did not explain what sort of illness it was, he only asked how she got the illness and what her behaviour was like when she was under its effects.

*Does any translation take place when you visit the doctor?*

Yes, but very little, sometimes there is, sometimes there isn't.

*What do you do when there is no translation?*

Then I can only observe. If there is no translation then I save up my queries for the next visit.

- Chinese carer

Sometimes the lack of communication between practitioners and carers is not solely a result of language difficulties, or lack of time for consultation. Some carers reported 'having to guess' about the nature of their relative's 'illness'. It seems that while attention is given to the person with the mental health problem, carers are seldom consulted, and may feel 'overlooked'.

*Did anyone ever explain to you what is happening with your wife?*

Nobody ever explained it to me, either here or in Poland.

*If no one told you what is wrong, then how did you know that your wife is sick?*

I recognised the symptoms myself from her behaviour. When she is starting to get sick nothing matters to her. Sometimes it is not so bad, and other times it is very bad... Sometimes she sits for a long time without saying a word, sometimes she cries and other times she is aggressive. In Poland I was told that there are many people like her and that was it. In Poland it started. But it got worse in Australia. I don't know why. Maybe because it is a different country, different language and living conditions are different. This might have had an influence on her condition.

- Polish carer

*Did anyone ever tell you what is happening with your husband?*

No, no one, not once. At the beginning the social worker in hospital, who seemed very nice, told me that we will have a lot of talks. But we never did. The social workers are always changing. Sometimes I ring up and get somebody new that I don't know and who knows nothing about my husband's case. I don't know who I'm talking to, and I have to start telling her everything from the beginning. That irritates me. They should have everything on file, and they should know it all, but they don't know anything. My son, who is a physical education teacher and has studied sports medicine, made an appointment with my husband's specialist to find out what kind of exercises his father is doing. It turned out that there was nothing on file.

- Polish carer

*Did anyone ever explain to you what is happening with your husband?*

Not really. But I didn't need any explanations. In Poland I worked with elderly people and I know what dementia is.

- Polish carer

All of the carers interviewed expressed their appreciation at being given an opportunity to speak about their concerns in their own language. Unfortunately, it seems more often the case that language barriers and an insufficient number of bi-lingual practitioners contributes to carers 'keeping their problems to themselves', or within their immediate family. Many carers interviewed appeared visibly exhausted.

*Has anybody offered you any help in relation to all this?*

If I could only have some help like this, to talk to someone, but it's very difficult because we don't know the language, we don't know anything. When we go to the shop we can't cope, we can't ask...everyone's talking, we're not talking. It's like being blind.

We can be alone for three or four days, she and I alone. I sit here, she sits there....nothing. Neither talking....What is there?

*Don't you have a television?*

We do have a television.

*But she probably doesn't understand that, does she?*

No, we don't understand anything.

*And I guess she can't read.*

No we can't read.

*Does anybody visit?*

Because we're old, very rarely. Everybody avoids the old.

- Bosnian carer

*So, actually no one ever explained to you, that such attacks can occur, and what consequences there can be?*

No, no never.

*So you were never prepared?*

We were never prepared. As I'm saying, the caring had always been on the basis of friendship, the fact that we knew each other, from a good heart, that we needed to help our mate, since he also came from Poland. He was our friend and an exceptional person, indeed.

- Polish carer

In some cases the inability to communicate in English was seen by carers as a contributing factor to the diagnosis of a mental illness. This possibility has also been discussed in the literature on ethnicity and clinical diagnosis. In English-speaking countries, CALD clients in distress are more likely to be diagnosed as schizophrenic on the basis of the cultural misunderstandings of the doctor, than they are to be diagnosed on the basis of the presence of any of the 'classic symptoms' of schizophrenia (Boyle, 1996; Littlewood & Lidsedge, 1989).

They said it was schizophrenia. But it wasn't schizophrenia. She had a nervous breakdown. She had a lot of pressure in her life. Her children, her husband, the lot. Not so much the children, I think, as the husband. And then she had a nervous breakdown. Particularly not being able to speak English. All of it together....

- Croatian carer

## Suggestions for Appropriate Support Services

The carers were asked about the kinds of assistance that would best suit their needs. While they did not always clearly articulate their needs – perhaps because they were not aware of the forms of assistance they are entitled to, and are not used to being asked – it is clear that CALD carers have diverse needs and expectations of support. When needs were articulated, these included both material forms of assistance (e.g., cleaning, gardening, transport) information (e.g., lectures or seminars on mental health and illness) and social support. The latter included the need to have ‘time out’, an interest in attending carer support groups, access to ethno-specific telephone helplines, and visits from people who will spend time with their distressed relative. Underlying these diverse suggestions was a plea for relief from the routines of caring, not a desire to abrogate responsibility. This carer remarked that the need for greater acceptance of their ‘mentally ill’ relative, and respect for them as a person was fundamental, but often neglected:

Acceptance has always been important, looking after them and encouraging [them]. By doing so you notice that they get better much quicker. I truly believe that an illness of the mind and thought requires medicines of mind and thought - that is, support and acceptance from family and society. Some mental illnesses require medicines, but more often than not require psychological support. If you give them respect and treat them like normal people they will recover very quickly... A mental illness is but one type of illness. People in a society accept people with physical illnesses, like cancer, so why can they not accept someone into a society because they are mentally ill? That too is but another illness. They themselves don't want this illness. I feel that society needs to change and to alter their views of people with this type of illness. Actually there is nothing wrong with them and they can resume a normal life once they have recovered. But if you do not give them on-going support it can be very difficult for them. Instead of giving support we often give them bad experiences.

- Chinese carer

Such comments, which reflect a ‘sociological’ perspective on the plight of the ‘mentally ill’, were relatively rare among the carers, and suggest the need for broad social change, rather than the isolated provision of discrete services or forms of support. A community education strategy would be an effective means to change social views in the direction suggested here. However, facilitating the social integration of people diagnosed with a mental illness seems necessary in order to dissolve the ‘boundaries’ between the ‘mentally ill’ and the rest of the community. Such societal change would achieve what the above carer describes as the resumption of ‘a normal life’. Indeed, a number of carers expressed the importance of their ‘mentally ill’ relative having social contact with others, either through people coming to visit or making contact through social centres. This was seen as beneficial for relatives in distress, and would also offer relief for carers:

*Did you get any help? If so, what?*

All I'm trying to do is get a few more people to visit her or give her a call. And she refuses to accept that she has a mental illness. So there's nothing we can really do for her, except care for her.

*So you tried to get other people to visit her and help care for her? How did you get this help?*

Oh, mainly among the Chinese community, and the Chinese Catholics and Sister X....And, if possible, sometimes some priests visiting Perth that speak Chinese.

- Chinese carer

*Having the responsibility of caring for an ill family member, what part of the government's services do you think is lacking or insufficient, placing special emphasis on your inability to speak English?*

If only there was someone, or if the council would send someone, to communicate with her. I believe there would be progress and it would relieve her of her stress.

*Is this psychological pressure?*

Yes, it would help. In the past she always nagged about going home to China, but now she no longer does that.

*She no longer says she wants to go back home?*

No.

*Is the message you are trying to convey that she needs someone to talk to her, to open her mind up, so that she would not feel so lonely and isolated?*

Yes, that is my meaning.

*If the council could supply this service, do you believe it would help?*

Of course, it would not only help her but me also, as it would relieve the pressure on me...

- Chinese carer

*Now that you have to care for your wife, what government services do you think can help you?*

If there are more places like X and senior centres for us to go to, and if someone could come to talk with us, that would be good. The pressure on me would be softened.

*Would it be good if more Chinese knew about X and its services?*

The earlier they find out the better, because that would mean that more Chinese can come together and discuss and help others in times of need. This is especially true for Chinese who have just come to this land and are unfamiliar with its language and customs... The help X has given us is indescribable. We were thus able to gain from this help knowledge of where there were more Chinese people and where there were Chinese restaurants. When we first came here we didn't know anything about Australia, we didn't even know how to catch a bus.

- Chinese carer

I think that first of all, the mentally ill should not be treated this way. Care for them is based on giving them tablets and sending them home. There should be more to it, meetings with psychologists, psychiatrists, with people who are...[available] to have an open conversation. He should have a person, a friend, who has a similar disease, with whom he can have a chat. Have contact with a person who knows perfectly how to treat him. People like me can hurt him...

- Polish carer

Support groups, with whom carers could share their experiences, and telephone helplines were also seen as useful resources. As one carer explained, community-based support groups would be helpful:

...I know from my own experience - to have those little support groups, or clubs or whatever you call them...that would be a great help.

- Croatian carer

The same carer explained that a 'helpline on the phone' would be useful, recounting past occasions of desperation in not knowing whom they should ring:

Sometimes I used to think, "Who can I ring?" When I was really desperate, I couldn't always get the doctor...And in the end, when things got really bad, I didn't want her to go to Graylands, but that was the only...sort of alternative. And it was heartbreaking for me, because when she came out of hospital, she said, "Why did you put me in hospital?" It wasn't our choice; it was her husband's. I felt it wasn't necessary, really. If the right sort of help had been there she would never have had to go to Graylands, because she wasn't one of those cases that had to go, like, to be tied up. And it made her worse.

- Croatian carer

The following carer expressed a need for a trusted 'helper', perhaps a live-in carer, so that she could "get away sometimes". Although she did not have any expectations that care would be available from the government, or from other agencies, she also recognised that some help would allow her the respite to visit their relatives in Poland. She foresaw a time when she would not be able to cope and, in the absence of respite, she expected to "fall into depression":

*What sort of help do you need?*

I need to get away sometimes and breathe some fresh air without the need to be always on call. My husband is not very difficult, although he has his moods, and you need to try and change his mood. I seem to be able to succeed most times, but when I don't I just wait for it to pass...I would like to be rich and have servants to help me look after my husband... to have some freedom to go to the pictures with friends. I find it very difficult sometimes, but I go to the Polish House and talk to my friends, and it gives me some relief. Sometimes prayer gives me some moral support... I would like to be able to go away sometimes to see my family and to have someone here that I can trust to look after my husband. Maybe someone who could live in our flat and look after my husband while I'm away. At this time I don't expect this, but I think there will come a time when I am not able to cope by myself, and if I don't get any respite I'll fall into depression. I miss my son and my grandchildren very much. I looked after them when they were little and they are very dear to me. In Poland I would not have much help from the government, but I would have family and friends who would help me look after my husband. Generally I don't have any expectations from the government or other agencies or people, but if it were possible I would like some help so that I can visit my family [in Poland]. At present I am physically healthy and able to manage looking after my husband. What will happen in the future I don't know...

- Polish carer

Another wished to better understand their family member's illness in order that they could offer better care. However, they also thought that support from the Church was important:

*What sort of support would be most useful for you?*

If I could go to some seminars or lectures that could help me understand this illness...And so that I also know how to handle her situation.

*Any other support?*

I think the support from the Catholic Church is very important, and the priest and the nun.

- Chinese carer

Many of the carers suggested that a range of material supports would be highly appreciated. These included domestic help with gardening, cleaning, and washing. However, it would be wrong to assume that carers in general would welcome another person into their house, or that

just any help is appreciated. As one carer pointed out, although she acknowledged that home help would be useful, she felt “very private” about her house and “wouldn’t like someone coming to my house and...doing things for me...I’d feel it just wasn’t right”. Upon further exploration, the same carer explained that other kinds of help, such as Meals on Wheels “would be even better”. Another carer said she needed some help with cleaning, washing the curtains, washing the floors and gardening. However, she qualified this by saying that she needed “someone who can work independently without having to ask me what to do all the time”. Thus, although many of the carers expressed a desire for help, the level and kind of support required should never be assumed. A thorough assessment of the particular needs of each carer should always precede any offer of service or support.

## **9. INTERVIEWS WITH CARERS: SUMMARY OF FINDINGS**

### **1. The effects of ‘mental illness’ on carers and their families**

Carers reported a diverse range of experiences. These were shaped by factors such as:

- The pre-existing relationship between carers and their dependant relatives.
- The nature and severity of the psychological distress of the relative.
- The particular circumstances of the carer, the wider family unit, and the relative being cared for.
- Becoming a carer may have a profound impact on the lives and opportunities of carers and their families.
- Carers reported difficulties with the change in family dynamics that came with “having a ‘mental illness’ in the family.”
- Some carers reported distress amongst their children, episodes of verbal and physical abuse, financial burdens and disruptions to sleeping patterns.
- A number of carers expressed extreme frustration with their situation.
- In the absence of support, it becomes impossible to adjudicate between the presence of a ‘mental illness’ in one family member, and the effects of threats of physical violence from another.
- Caring is a twenty four hour a day job.

### **2. Access to support services**

Barriers faced by CALD carers in accessing support services:

- The lack of knowledge held by carers about the existence of support services.
- The belief that caring is exclusively a family responsibility.
- Previous negative experiences in trying to access support.
- Some carers would accept outside assistance only as a final resort.
- Carers reported having to be pro-active in order to receive information about the mental health of their relative.
- Many carers reported significant difficulties with the English language.
- Families were often concerned about the effect that “having a ‘mental illness’ in the family” would have on their relationship with their community.
- Children whose parents have been diagnosed with a mental illness may experience profound disruptions to many aspects of their lives.
- Having access to family networks does not necessarily mean that help will be forthcoming.
- Family dynamics are changing, and this may influence attitudes towards caring as a family responsibility.
- Finding the right person for carers to discuss their concerns with – even in the absence of language barriers – is a challenging task.

### **3. Communication issues**

The difficulties CALD carers experience in communicating with service providers is due to the language barrier, and to the lack of time allotted for consultations. This problem becomes more pronounced when interpreters are used.

- Some health professionals refuse to use interpreters.
- There is a need for more biligual and mental health professionals.
- In some cases, the inability to communicate in English was seen to be a contributing factor to the (mis) diagnosis of mental illness.

### **4. Suggestions for appropriate support services**

- Carers needs include material forms of assistance (e.g. gardening, cleaning) and social forms of support.
- Carers expressed the desire for social contact with others.
- Language specific support groups for carers were called for.
- Community-based support groups and telephone hotlines were seen as useful support options.
- Respite was seen as a useful form of support.
- Carers requested more information about the 'illness' of their family member, in order that they are able to offer better care.
- A thorough assessment of the particular needs of individual carers should always precede any offer of service or support.