

**WORLD FELLOWSHIP FOR SCHIZOPHRENIA  
AND ALLIED DISORDERS**

124 Merton Street, Suite 507  
Toronto, Ontario, M4S 2Z2, Canada  
Te.: +1.416.961.2855; Fax: +1.416.961.1948  
Email: info@world-schizophrenia.org  
Website: www.world-schizophrenia.org

## **FAMILIES IN LIMBO**

*By Margaret Leggatt, Ph. D. Past President WFSAD*

This paper demonstrates some of the contradictory or paradoxical situations in which families of seriously mentally ill adult offspring find themselves, and which justify the title 'Families in Limbo'. While 'Limbo' was the region on the border of Hell, its meaning now equates with a sense of being unable to move, to be in circumstances from which there seems to be no way out, to not know which way to turn – the feeling of being caught in a 'Catch 22'.

While the emphasis in this discussion concerns situations found with adult children, many of the problems are the same for all other family constellations. Contradictory and paradoxical situations encountered by families commence with their role in seeking help.

### **1 ROLE OF THE FAMILY IN SEEKING HELP**

Families observe changes in their relatives' behaviour to the point where they feel that outside professional help is needed. But because the changes are behavioural, not strictly 'medical' or 'physical', it is difficult to decide what kind of help is required. And unlike most other illnesses, their relative does not believe he or she is 'disturbed' or 'ill', and will not seek help.

#### **First problem: lack of insight**

Family members seek help from doctors for relatives who claim they are not sick and do not need help. Doctors will not visit someone who has not requested their assistance. Persons who are perceived as sick by their family members are legally independent adults, therefore it is their right to choose whether or not they seek help.

In acute episodes, and for many families over the longer term, the 'choice' of their mentally ill relative not to seek help results in them becoming financially, domestically, socially and emotionally dependent on their families, thereby infringing the right of family members to lead **their** own lives. At present, family members are generally seen as not entitled to 'rights'. They are automatically expected to take on a caring role, whether or not they are able to cope with the multitude of problems created by mental illness.

### **Resolution of the problem:**

- a) Family members need to be trained to understand signs of mental illness in their relative, and to learn to articulate this clearly to doctors.
- b) Doctors need to be trained to understand that:
  - ❖ mentally ill people will often not seek help
  - ❖ family members have important information to give that will help doctors formulate a more accurate assessment of the person's mental illness.
  - ❖ family carers have rights too, and that mental illness in a close relative can infringe those rights
  - ❖ we as a community believe very strongly in the rights of the individual. Family members are individuals too.
  - ❖ mental health professionals have a 'duty of care'. It is in the best interests of the patient to inform and support their family carers.
  - ❖ it should not be automatically assumed that patients and families will be at loggerheads forever. Insight is frequently regained (but not always). What patients want for themselves is usually, in the long run, what families want for them anyway.

### **Second problem: confidentiality as a barrier to obtaining help**

Mental illness can cause regression to childlike dependency, not to mention a wide range of socially inappropriate and destructive behaviours. Most legal practitioners do not appreciate the nature of mental illness where psychotic symptoms are involved. A failure to understand that psychosis leads to regressive behaviour means that the law views the mentally ill person as an adult able to make mature decisions about his or her own welfare. Doctors generally abide by this law as the fear of being sued is becoming more and more of a deterrent for doctors who might otherwise make some 'commonsense' decisions.

Families have to deal with the paradoxical situation of an adult mentally ill person who has little or no insight, will not/ can not seek help, has adult independent status, but whose mental illness behaviour is regressed and inappropriate.

**Help is not available.** Family members are not listened to, or sometimes if listened to, are not believed. Even if they are believed, action is not taken. The mentally ill person deteriorates, sometimes to the point of violence, before any help is available.

**When help is finally available, usually after violence, family members are largely excluded** on the grounds of a breach of patient confidentiality- if they are involved in giving or receiving information. Under these circumstances, families feel powerless.

Intrafamily interaction becomes very stressful. Each family member blames the other for what has happened and is continuing to happen. This frequently leads to families being torn apart and breaking down.

### **Resolution of this problem**

- a) Decisions for treatment and care need to be made on the basis of competence, not simply on the basis of the person's age.
- b) Competence can only be totally assessed by including detailed information from those in the ill person's family and/or social environment.
- c) It is not only mental health professionals who need to really appreciate that, but lawyers and civil rights advocates as well. *'Legal do-gooders rise up to protect people who mostly don't need legal help, but protection from their own sick brains. Those who propound the theory that a person should have the freedom to do as he pleases and the freedom to be sick, leave forgotten one very important freedom – that when a person's judgement is grossly impaired by a process outside his/her control, he has the right to expect that society will come to his aid and will take over until he is once more capable of exercising his own judgement.'*  
(Quote from a mother, Australia)
- d) Barriers imposed by strict adherence to patient confidentiality need to be withdrawn when it is in the patient's long term best interest, even though he or she may not agree at the moment. When the patient lacks insight and is unlikely to give permission to communicate information to family members, doctors must still ensure that they communicate information to, and receive information from, family carers.

## **2. ROLE OF THE FAMILY AS A CAREGIVER**

In spite of not involving families adequately, the psychiatric system still expects families to take responsibility for their relative. Family members become "case managers" and "primary carers". Their relatives have an illness, which requires continuous medication, which they may or may not want to take. ! Family carers are put into the position of nurse – to administer medication. Professionals tell family members that patients should be responsible for their medication. Often they are not! If parents supervise medication they are seen to be denying the person the capacity to become responsible; if they do not, the patient who is non-compliant or forgetful, becomes ill again.

Family members are called upon to provide psychological and social therapies, occupational and recreational therapy, and attendant care for which they are not trained. They do not have holidays, do not get paid, or have compassionate leave.

Family members are emotionally involved with their 'patient - how can they not be? As 'case managers' and 'primary caregivers', family members are expected to show objective judgement towards their own flesh and blood. Can you be objective towards someone with whom you are closely emotionally involved?

This paradox is carried further by professionals who have a tendency to view families who take responsibility as caregivers, as being over-protective. If family members try to encourage a reluctant mentally ill person towards independence, they can be viewed as rejecting. The mentally ill person can manipulate these emotional dilemmas, playing family members off against each other. This causes terrible anger, tension and disharmony in the family.

If families try to assert their rights to lead their own lives, to set limits to behavioural excess, to lead a person toward independence, the mentally ill relative through their intense fear and anxiety – which they are unable to express - can become more demanding, and emotionally manipulative. The family gives in because, after all, their relative is sick and cannot be expected to behave in more mature ways. This leads to the next problem.

### **Third problem: family carers inadvertently increase disability**

Family carers acting as nurses and case managers to help their mentally ill relative manage their illness and disability, can **inadvertently** further the tendency for their loved one to function less competently than may be possible. Caregiving can increase disability, because family carers are vulnerable to emotional manipulation by their mentally ill relatives. They are rarely helped or trained to manage these difficult circumstances.

### **Resolution of this problem:**

Professionals must understand these ‘emotional double-binds’ much more sensitively. Misunderstandings between families and professionals lead to ‘disengagement’ between them; family carers feel that professionals are unsympathetic and have no understanding of what coping with mental illness is really like; professionals often feel families are to blame for what has happened and are disinclined to help them. How many professional people could themselves carry out what they ask family carers to do? If parents cannot do what professionals have suggested as a solution, they shouldn’t feel they have failed, nor should they be seen as having failed. Family members are often in impossible situations. Professionals need to remember that and to work collaboratively with the family to find other solutions.

Families need help to become ‘appropriately assertive carers’ rather than simply becoming ‘passive minders’. Assertive caring means an effective treatment alliance between families and professional helpers, and self-help through mutual support (as can be provided through the family organizations). These two forms of help need to be available over time.

## **ROLE OF THE FAMILY AS PEER GROUP**

When a person develops a mental illness, there is often an accompanying inability to relate to his or her peers – the group of friends that gives life much of its meaning. For many mentally ill people, parents, brothers, sisters are the only people who feel they should provide a social network.

But there are many problems here. For example, the interests of aging parents are not the interests of young adults. Besides, the emotional climate is often too fragile (because of the mental illness) for rewarding relationships to flourish.

Brothers and sisters are being successful. For the person, being with them is a constant reminder that 'I am a failure', 'the burden', 'the misfit'. It is extremely difficult for jealousies, anger, and resentment on the part of the mentally ill person, not to develop.

For siblings, these are exceptionally difficult positions. How can they remove their success, so that their sick sibling will not be resentful? Can we ask them to be supportive when their own lives are busy and involved? How are they going to manage? Should they be the ones to help when parents are no longer able to (given the difficult emotional relationship between themselves and their mentally ill brother/sister)?

### **Fourth problem: reinforcement of inferior status**

Family members forced to provide a substitute peer group can be a subtle and constant reminder of one's inferior position as a mentally ill and disabled person.

### **Resolution of this problem**

The principle we need to develop here pertains to the need for mentally ill people to be helped, encouraged and supported to develop a life for themselves. This needs to be provided by appropriate social, recreational and vocational programs developed by resources outside the family.

The development of a life for themselves, through interests, activities and other friendships (and those other friendships may be other mentally ill people), means they become less dependent on their family. This brings a better balance to family interactions.

## **3. ROLE OF THE FAMILY AS LANDLORD OR HOUSEHOLD SUPERVISOR**

Families often have to live in their own home environment, with a mentally ill adult child whose capacity for compatible interactive family living has markedly decreased. Personal disorganization—a result of many of the symptoms associated with mental illness – leads to an inability to carry out household tasks.

Homes become chaotically untidy and dirty, particularly, as is very often the case, when the mentally ill person is a heavy smoker. Routines are disrupted. Without appropriate and effective treatment people suffering psychiatric disorders stay up all night and sleep all day. Family members are exhausted by this, as they are kept awake during the night but have to carry on normal daily routines. Paranoid ideation means families don't feel comfortable having their friends over for fear of an outburst by their relative

The lack of motivation, often reported by family carers as the most difficult and distressing of all symptoms, has an appallingly draining effect on their own morale. Rent or any financial contribution from adult mentally ill children is not always paid because of poor money management or lack of money. The family constantly subsidizes such things as clothing budgets, inappropriate expenditures and things like cigarettes.

Mental health professionals often look at these situations and suggest that relatives 'let him/her reach rock bottom' when family experience tells us there is no bottom as insight and awareness are substituted by false beliefs and unreal thinking characteristic of these disorders. The mental health professional's solution of "kick him/her out" does not reckon on the response of the sick individual which is knock on the door of the family home relentlessly, threatening suicide, or camp on the doorstep until family gives in!

Families where the partner is ill face the same problems; the well partner carries the entire burden of household tasks – tasks that become excessively burdensome due to the ill person's incapacities. Professionals do not see the solution as the partner being asked to leave home. For the caring partner there seems to be no way out, except divorce or separation – for many an untenable thought as they are aware that their partner is ill and could not survive without support. Frequently, the needs of their children have also to be considered.

### **Fifth problem: incompatible living situations**

The family as landlord cannot exercise its right to evict an unsatisfactory tenant who ruins property and fails to pay the rent. Eviction could lead to relapse and hospitalization or vagrancy, petty crime and jail. Families here, needless to say, are in double-bind. The partner as household supervisor carries a huge burden entirely alone.

### **Resolution of this problem:**

We read a great deal about the principle of 'normalization'. What is normal in most western societies is for adult children to move away from the parental home and to develop style of life that allows them to be financially, socially and domestically independent of their parents.

In most instances, adult mentally ill children should be encouraged to live away from their family members. This means we have to fund and provide a wide range of housing, with varying levels and kinds of support services to meet individual needs. And unless this happens, we are not allowing mentally ill people to achieve their basic human rights,

nor are our family members able to enjoy their basic human rights to expect the best possible care and support for their mentally ill offspring.

In many societies, parents see their children as their responsibility until the children are married. As with partners, the solution here is not moving away, but provision of a wide range of support services – home help, support for the children and respite care. In most societies worldwide these kinds of services are conspicuous by their absence.

## CONCLUSION

**It should now be acknowledged that family carers play a pivotal role in the treatment and care of their mentally ill relatives. But they do this with little help and support for their valuable contribution, let alone recognition for the difficult tasks with which they are faced. Unless the important roles of family carers are supported in the future, this valuable resource may not be sustained, to the detriment of those who suffer mental illness. The greatest challenge for the mental health community is to understand the problems, which have been described in this paper, and to find creative ways to implement the above resolutions.**

This paper was presented at the WFSAD One-Day Conference,  
Dublin, September 27, 1993, and updated, September 2000.