

www.world-schizophrenia.org

An international organization supporting families/consumers around the world.

To reduce the stigma associated with mental illness by educating and informing the public
 To advocate for best practice services for the diverse needs of people with mental illness in all areas, including direct health care (acute and long term), housing, occupational therapy, recreational programs, employment programs, etc., and to encourage and support innovative ideas in these areas
 To provide facilities such as drop-in centres, housing and recreational programs\*
 To provide respite care for families, exhausted from the task of care-giving\*
 To provide grief counselling for families where the severity of the illness has robbed them of the former personality of their loved one and where the relative has been a victim of suicide
 To liaise with medical professionals (psychiatrists, family doctors, nurses, social workers, occupational therapists, etc.) for maximum cooperation to improve the lives of those with mental illness
 To ensure that family carers are not excluded from the care of their sick relative

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<sup>\*</sup> Some family organizations have determined that to provide services will sap the limited strength of their members, volunteers and staff. Other family organizations have determined that this is the path they wish to follow and have developed funding policies and missions in order to accomplish this. Some organizations decide that support, advocacy and provision of services are all laudable aims for a family organization. To make sure that they focus on each aim, some organizations require that members wishing to develop direct services create a new affiliated organization to better focus on the task at hand

Local groups may also initiate services, but it is best to separate these from the main business of running the group so as not to over-extend members. Thus a new executive might be created of those interested in pursuing a housing or work initiative.

N.B. Neither families nor their relatives are a homogeneous group. Respect members' backgrounds and accept that they will not all participate in the programs the group runs.

#### 9. The Future

## **9.1** What can be achieved in realistic terms by family self-help organizations?

The modeling of realistic programs of use to people with experience of serious mental illness through:

- a) Developing model programs ourselves
- b) Taking part in the formation of programs
- c) Commenting on the inadequacies or the excellence of existing programs

#### Improvement in the system by:

- Being involved in the creation of humane mental health laws
- Lobbying for sufficient acute and long-stay care places in hospitals
- Helping to reduce the stigma and discrimination that surround mental illness
- FIRST—among members—families will "come out of the closet"
- THEN—in society—important people will go to bat for us
- Creating more funds for research
- Creating a huge and ultimately powerful lobby group for mental illness

With our energy through advocacy will come the recognition by governments and society of the mentally ill person's right to, and need for, treatment that will improve his lot in life; his right to decent long term housing; adequate income; and respect as another human being.

### 9.2 Sharing with Other Self-Help Groups

As groups become stronger they wish to share the knowledge and the benefits of family self-help and support with others. From the beginning -- when one group splits into two -- grow local, provincial, national, and international bodies.

#### 9.3 Adding a Website and Email Address

In areas where a lot of people have computers it is very possible that you have someone competent on the internet in your group. Websites are not difficult to establish and one of your members may find it rewarding to develop an interesting and informative site that the general public may access. With regular updates, a one-page website may grow into a many faceted library of reference material.

#### 9.4 The Emerging Roles of Family Self-Help Groups

Self-help groups for families coping with a relative with schizophrenia are somewhat unique. They help themselves while at the same time promoting the well-being of others who cannot help themselves - their loved ones. The focus of such groups must retain a balance between these two objectives. As family groups grow and strengthen, they develop new objectives in advocacy and education. Goals for such organizations may include the following:

- □ To identify the needs of families affected by schizophrenia and allied disorders and to respond by providing emotional support, problem-solving and coping skills, information and practical help
- □ To provide individuals with a clear understanding of serious mental illness, treatment programs, and the choices available at various stages of the illness
- □ To provide education and training for families
- To advocate for improved mental health laws
- □ To advocate for more funding for research to find the causes, better treatments, and the cures

## 7. Further Development

#### 7.1 Groups organize into a federation or loose alliance:

- All groups decide to get one umbrella group to coordinate activities so that all are working together.
- Umbrella organization is made up of representatives of all the local groups.
- Groups seek funding to hire a Director for umbrella group.
- Members decide to formalize membership by requiring annual dues to be shared by grass-roots group and umbrella group.

#### 7.2 Umbrella Group reaches out

An umbrella group does not give the same "hands-on" help through a support meeting as do the other groups. Its function is usually to coordinate programs and keep communication between the groups active, as well as being the spokesperson to outside organizations or government.

#### It develops its own mandate:

- It registers legally and draws up a constitution and bylaws
- Speaks to government on behalf of all groups.
- Develops a newssheet for the whole organization to be distributed among members and to educate the general public. This will require a database of names and addresses.
- It raises funds for operations

#### It plans activities

- Organized publicity
- Takes part in community activities, conferences, health fairs and mental health days
- Develops public advertisements on radio using central telephone number

#### 8. Gaining More Influence

#### 8.1 Umbrella Group becomes more political

#### Develops avenues of approach to government:

- Presents position papers and briefs
- Responds to government action
- Hires Advocacy personnel to work with government representatives
- Instead of reacting to events, it instigates its own action first (proactive rather than reactive)

#### Undertakes major projects:

- Conference on schizophrenia and allied disorders
- Published books, booklets
- Major fund raising for research and operations
- Seeks government and private funding
- Serious lobbying efforts
- Service development:
  - Housing
  - Respite care for families

#### 8.2 Further growth of Local Group

With suitable office premises the group may initiate programs for families and their relatives:

- Creative writing for persons suffering with schizophrenia or related disorder
- Camera club; crafts; greeting card design and production, etc. computer literacy
- Home management (cooking and home care)

#### 5.5 Forming an Executive

When the size of the group gets to about twelve people it should be formalized by creating an executive. Not all the positions listed below are necessary at first.

Coordinator - Chairperson calls meetings; recruits volunteers; represents the group at outside functions; ensures group sets up regulations and goals. This person needs good interpersonal skills to work productively with others. The coordinator's function at a meeting is to act as the leader of a democratic group with one all-important overriding concern: he/she must be sensitive to a very vulnerable group of people who are more than normally stressed, often with few or no supports; many of whom have lost the confidence to press for their concerns to be met.

**Vice-coordinator - Vice Chairperson** chairs meetings in the coordinator's absence and therefore needs similar skills; represents the group at outside functions; prepares to take over coordinator's role at end of his term (this ensures continued leadership). Helps recruit members.

**Secretary/ Treasurer** handles and keeps accurate records of group funds. S/he prepares financial reports; is a signing officer for bank accounts. S/he takes minutes of the group's annual meeting and keeps organized records of correspondence. Keeps members well informed of activities in liaison with the coordinator. This job should be separated into two as the group grows.

**Medical Advisory Committee** is important so that medical information and advice is available from professionals who support your mission. This support will add credibility and be invaluable in supplying medical knowledge. Enlist the support of at least two, preferably psychiatrists or psychiatric nurses, who have a particular interest in schizophrenia and bipolar disorder. They should agree with and champion the group's goals and objectives.

**Communications Officer** organizes telephone committee which keeps members informed of all meetings, etc. This person writes the Public Service Announcements accepted by local radio stations and by local newspapers and the bulletins of the places of worship. Organizes a publications committee for the distribution of materials.

**Fund Raising Officer**: must feel comfortable contacting local businesses, etc. to obtain donations of supplies or funds for running expenses. Other duties may be small scale at first: organizing bake sales, raffles, etc., and can only be done with the support and help of the members at large or a committee struck for the purpose.

#### 6 Starting other Groups

#### 6.1 Group splits into two as people from further afield get interested.

- People are travelling long distances to get to the meetings.
- A network of friendships emerges.
- A second or third support meeting is created in another location.
- They share and develop their information about services, about the disease, about research, etc.
- Someone decides to take on a leadership role in another district or town.

#### 6.2 People in nearby towns want their own group:

- The first group supplies them with information to help them set up.
- While supporting their aims, it acts as a catalyst rather than as an expert.
- It is important that the new groups are simply affiliates of the first group. No group has any control over the other and this may start petty jealousies. In the more rare cases where a national group has begun first, this may not apply.

#### A Confidential Log Book

Many groups keep a confidential record (log book) in order to keep track of the questions they have answered and those that still need answering. This ensures that names, addresses and telephone numbers are not mislaid and that volunteers are always informed of any problems that have arisen and what solutions were found.

#### **Reading Materials**

People attending meetings or personal interviews at your office or talking with office personnel on the telephone like to take away materials to read afterwards. This helps them digest what has been discussed. In addition, this material is a guide for volunteers who are designated to give advice. Thus, most organizations develop their own materials with the help of professionals. These should be numbered and reproduced in sufficient numbers for the group.

## 5. Growing Bigger

#### 5.1 Building Membership

After the support group has been meeting for some time further objectives may emerge. These may be:

- To be better informed (about services, course of the illness, etc.)
- To inform others

#### 5.2 Public Education Meetings

While continuing the support meeting, a regular information meeting may be arranged, and speakers invited (research scientists, social workers, psychiatrists, lawyers, etc.) Members wishing to provide written information may strike a committee to accomplish this task. Always remember that many members have very onerous burdens. They should not be coerced into activities they cannot handle.

Be sure to use the resources in your community: the Mental Health Association; the Lions, Kiwanis, Rotary or other service club; University, high school or college students (volunteers - can deliver and post advertisements); churches; pharmaceutical manufacturers; local businesses; police department; local politicians, philanthropists, etc..

#### 5.3 Be Well Organized

Whatever character the group evolves, it must be well organized. People will be discouraged if information about meetings proves incorrect, or someone fails to unlock the door at the meeting hall. Members who cannot take part in developing written materials, may be very happy to be the person who telephones everyone to remind them about the meeting, or goes ahead of everyone else to open the meeting room and put out refreshments.

Formal groups with a board of directors are often better at complex tasks than at meeting emotional and personal needs of members. Decisions about finances or the running of the group should be made separately from the support meeting. Some groups arrange "executive" meetings before or after the support meeting to reduce meeting nights to a minimum.

### 5.4 Formalizing the group: The group needs:

- A more formal system of governance.
- A greater degree of consensus on decisions of the group (avoid majority decisions—they can create bad feeling).

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- A group telephone line with machine to automatically answer calls
- An office no matter how small
- Training for Support Volunteers
- A system in the office for everyone to follow
- A fund raising policy to support the above
- And much later on a decision on whether to hire staff to offset the pressure on family volunteers

It is certain that families want **more** than support and that an organization cannot thrive on that alone. People need to play a productive part in:

- Public Awareness
- Lobbying for services
- Lobbying for better treatment
- Raising money for research
- Raising money to provide services

## 4. Practical Needs of Your Support Group

#### A Telephone Line

Many people in the community may not have a telephone line so that a telephone number for the group may not be practical. However, where it is possible a telephone with a message machine can be helpful in advertising your support and business meetings. It may be possible that the local clinic will be willing to provide callers with the dates and times of your meetings. Alternately, a well-wisher may be able to provide your convenor with a telephone line and answering machine.

Volunteers may take turns to return these calls when a message is left. The hospital or local clinic may provide a room where you may answer the calls one or two hours a week.

#### Alternative to a Telephone Line

While in many areas a telephone line and answering machine are not expensive and are easily available, this is not the case in many parts of the world. Therefore, the public meeting takes on an extra significance, since it is only by going to the public meeting that you can meet and talk to someone who may be able to assist and to give moral support.

#### A Regular Public Meeting

A public meeting is entirely different from a support meeting. It is designed for the group's members to learn more about mental illness through talks given by those with experiences that will help the group. A doctor may be asked to come and talk about medications, or about the symptoms of different mental illnesses. Public meetings are held less regularly than support or business meetings, perhaps 2 or 3 times a year and should be well advertised for maximum effect.

#### An Office

To establish an office is perhaps one of the most difficult things that a beginning group encounters. It is usually necessary for someone to loan you a room in the clinic or hospital or in the premises of a Service Club, or church, or in an unwanted room in someone's business. Support groups rarely have core funding to enable them to rent premises and maintain the equipment necessary for an office.

#### **Fundraising**

In order to pursue the activities you have chosen, it will be necessary to raise money or receive goods in kind. People are often willing to give tables and chairs, provide photocopying etc. All members of the group (at the beginning) should be on the lookout for material help.

#### A Volunteer Manual

As the experience of the group and its members grows, a store of information will evolve about local services and about the nature of schizophrenia and the problems that can arise. This information should be catalogued in a volunteer manual for easy reference, and the information noted by volunteers. Thus you begin a small database of useful information.

#### **Volunteer Orientation and Training**

At the beginning members exchange information and tips on coping with each other, but when the group grows and people are coming to your organization asking for advice, it is necessary to formalize how and what information is supplied by the volunteers and in what manner they do it. A training manual relieves the tension new volunteers experience and helps them orient themselves to how the group's office/services function. In addition there should be a formal, but not necessarily very long, training period conducted by the chairman or support group coordinator.

- □ To allow members to hear a variety of different solutions from ordinary people coping with similar situations [none being of a dogmatic nature]
- □ To let participants realize their experience and suggestions are very important; that their trauma is normal and that formal care givers can learn a lot that is valuable through the family's practical experience
- □ To direct participants to a more appropriate group if this one is unable to help
- □ To welcome new members and encourage them to speak, while first recognising that it is probably a particular problem that has brought them to the meeting
- □ To enable participants to leave the meeting feeling substantially better than when they arrived, or at least, to make sure that there is an exchange of phone numbers or an address to visit for follow-up

#### 2.5 The self-help group relies on the experience of members more than on the knowledge of experts.

Consensus and cooperative effort are what are used to find workable solutions. People learn from each other, so that the behaviour of members, the group activity and the structure and setting of meetings will all have a bearing on the group's success. Compromise, humour and sensitivity to everyone will help develop an unwritten law of the group's conduct. Certain behaviours can disrupt the harmony. There can be: talking too much and too often; dominating; not listening, criticizing, etc.. Identify these issues as they arise and resolve them. Sometimes it is only the anger, hopelessness and frustration of the person that brings forth this kind of behaviour.

The leadership style of the convener/ coordinator affects the meeting. Remember that the leader is not there to answer people's questions but to facilitate the discussion. She/he is an "enabler", someone who must recognize that each participant has his/her own needs and reasons for being there. Balancing the discussion; summarizing and clarifying points; keeping the group on topic, i.e. the well-being of the care givers; and giving everyone a chance to speak, these are the tasks of the convenor which will help the meeting run smoothly and amicably. The atmosphere created by these means also helps achieve the common goal of learning to cope, to understand and to better help one's relative.

## 3. Establishing the Purpose of the Group

#### Decide what the group as a whole needs:

- Information
- Publicity (to get more families involved)
- Money (for supplies, etc.)

### Decide what the individuals in the group need:

- Moral support
- Advice
- Recognition of their struggle

#### Obtain professional help:

- Doctors or nurses experienced in schizophrenia and willing to volunteer their time—these may become the medical advisory panel later
- A medical person to co-chair meetings at the start until a family convenor is comfortable doing it

#### Conduct regular meetingsÑ

- Informally create policies, attitudes and a loose system of governance
- Discover the need to advertise widely to become more diverse through a bigger membership
- Discover the need for a focus to satisfy the needs and stimulate the interest of their members

#### Concentrate on problems that are important to you - The focus may be:

- Lobbying government for pensions, services, better quality control/ availability of medications, etc.
- Developing their own services:
  - Drop-in centres (family or relative)
  - Housing
  - Education (information pamphlets), etc.

A support group may be set up by a professional in the field, who has patients whose relatives can be persuaded to meet other relatives in an educational setting. The group may also be set up by several relatives on their own. To begin with, a group may be completely informal. A professional may lead the group to ensure that information provided is correct and to offer the advice of experience, until the membership is able to take over. Support of professionals will continue to be important - for special advice, material resources and for referrals to the group.

#### 2.2 Starting a Group

#### One or two families, realizing the enormity of the problem, try to do something about it:

- Write article/ letter for newspaper (e.g. John Pringle—U.K. organization "Rethink" in 1979)
- Talk to the psychiatrist or psychiatric nurse involved in relative's treatment—find medical people sympathetic to families
- Arrange to meet with other families in the same situation through advertising in the clinic
- Advertise the meeting on local radio (e.g. free Public Service Announcements; if there is a regular medical advice program on the radio, apply to have your topic mentioned)
- Post a notice in your grocery store, church or library stating the time and place of meeting
- Talk to any local health organizations or Service Clubs

#### 2.3 **Holding Meetings**

Obtain a central location that is easily accessible (e.g. local community center; service club premises; church hall). Some groups prefer not to attend meetings in hospitals or clinics. Others feel that meeting in a hospital or clinic adds credibility to the meeting, or it may be that the group leader is a professional at the hospital. Meeting in someone's home is an option, provided that members of the group agree to alternate locations and no one family must host the meeting on every occasion.

The room should be pleasant with comfortable seating and privacy. It should also be possible to serve refreshments. Arrange regular meetings to be held on the same day each session (e.g. each Tuesday; the first and third Thursday of each month). People should be made welcome with enough seating. In a public location (e.g. church hall) the seats should be set up in a manner that invites communication (a circle is ideal). In many cultures the convenor/ coordinator likes to play a welcoming game or introduce the proceedings with a welcome song. You will know what is best in your culture or society.

The meeting will be the focal point of your group for while. It should last no longer than two hours. An informal ten minutes should be set aside at the beginning during which time the coordinator welcomes everyone at the door, helps create an atmosphere of trust and openness, and releases tension for newcomers who do not know what to expect. Members will then discuss their problems and offer advice to each other. A break for refreshments should occur after the support session so that members can mix and exchange information. At the first meetings an interim convenor/ chairperson and alternate should be selected, and members who wish to be further involved in the group may be appointed to open the premises, prepare the room, bring refreshments where possible, etc. One cannot over emphasize the need for a friendly welcoming atmosphere for families who are struggling on a day-to-day basis with very difficult problems.

#### 2.4 Objectives for the Meeting

•	•		
To ensure confidentiality for the participants			
To make participants feel suffic	iently at ease to talk about worries about their relative without fear of criticism		
To let members receive enough	n feed-back, by word or gesture, to know they have really been understood		
To recognize participants and grather than to suggest what else	ive realistic praise for what they have achieved and how they have coped e might have been done		
To allow participants to simply I	isten and absorb or rest, if that is what they need		
To let participants experience fe	eelings of hope realistic hope, in that even if there is little change for the		

person with illness, the family as a whole can learn to cope and lead a relatively satisfying life

#### 1.4 Benefits To The Person With Serious Mental Illness Derived From Family Self-Help

All the benefits accruing to the family may in some measure improve the life of their sick relative:

- Better relationships with family because family avoid certain behaviours that make life difficult for their sick relative
- More consideration by physician (psychiatrist) because the family has a better relationship with the medical profession
- Recreational activity that was lacking before may be found family groups have knowledge of these
- Housing for self, rather than the stress of living at home, gained through the knowledge obtained by the family association

#### 1.5 Benefits For Mental Health Professionals

At present this is still a double-edged sword. Some professionals are defensive because they fear criticism of their management. These disorders are difficult and many patients benefit only slightly from standard treatments (newer atypical medications now becoming available are somewhat better in their side effect profile, but do not control all symptoms). Patients deny their illness, often refuse to take medications they have found unpleasant and often malign their doctors. Families can help explain treatment. The support of professionals will help reduce their frustration.

Now, there are many signs of:

- Partnerships forming between family groups and doctors
- Information exchange families also have much expertise about their relative
- · Sharing experience with regard to the illness
- Realization that families are on the side of the professionals when they provide suitable care
- Realization that families can be a valuable ally in seeking research funds, better laws, better treatment, etc.

#### 1.6 Reduction Of Stigma and Discrimination among Participants and Others

When a large body of people works at grass roots level to solve a problem, an almost imperceptible change begins to occur in attitudes. The complete change in media reporting that has taken place in Canada over the last 15 or so years is proof of this. The families and their supporters were the first ones to speak out. They have been joined by the patients themselves (where this is possible) and now we see evidence that the psychiatric professions are joining this movement.

#### 2. How to Begin

#### 2.1 What groups can Provide

Family Support Groups have remained the backbone of many of the self-help organizations that have grown out of them. They are an invaluable means of self-help that can augment services provided by professional caregivers.

#### The groups provide participants with four broad opportunities:

- ☐ The unique support, understanding and strength given by people who are experienced in caring for a person with schizophrenia, bipolar disorder or depression
- □ The chance to learn from the combined wisdom of others experienced in coping with day to day problems
- The potential to make new friends when years of being a care giver has left people isolated
- ☐ The encouragement and support to work towards improving the lot for both people with mental illness and their families

#### 1.3 Benefits To Family Derived From Self-Help Initiatives that Focus On Education, Problem Solving **And Support**

BENEFIT DEFINITION	BEFORE SELF-HELP EDUCATION, PROBLEM-SOLVING & SUPPORT		DURING SELF-HELP EDUCATION, PROBLEM-SOLVING & SUPPORT	
EMOTIONAL	0	Emotionally drained	0	Gaining strength
	О	Prone to anger/ tears/ frustration	О	Learning to deal with emotions
	0	Unable to cope with sick relative	0	Learning coping strategies
	0	Conversations with and behaviours of sick relative cause friction	0	Learning how and when to respond to behaviours/ verbal contact
	0	Difficulty coping with other problems at home and in the work-place	0	Learning whom to trust and situations to avoid
	0	Losing self-respect	0	Regaining stability through realising
	0	Afraid to broach subject with friends		'I am not alone'
	0	Fearful	0	Beginning to speak about illness to friends
	0	Has let interests slide		
	0	Family relationships generally	0	Renewing social life Using strategies to improve
		deteriorate	0	communication & family
	0	Thinks there is an immediate solution		relationships
			О	Recognizing there is no quick fix
PHYSICAL	0	Constantly tired	0	Coping strategies help to regain
	0	Not eating properly		strength
	0	Gains weight/ loses weight	0	Begins to look after self
	0	Minor ailments.	0	Recognizes the signs of stress
			0	Gets help when needed
PRACTICAL	0	Cannot handle relative	0	Learns new strategies in psychology to help attitude and handling of relative
	0			
	0	Medical profession seems unable to help		Finds some solutions to problems
		them Cannot find housing, recreation or other		through input of many families in
		programs for relative		same boat
	О	Problems with money allocation	0	Learns the local medical system;
	0	Ongoing and new problems difficult		how to approach physicians for best results; input for best treatment
			o	May join with others to create
				services. eg housing, clubhouse
			0	Self-help organization can offer
				different help dependent on the
		No political action, or little effective		stage of illness and length of caring
POLITICAL/ SOCIETAL	0	No political action, or little effective action	0	Sees that the problems are not hers/ his alone - that they are
JOOIL I AL	0	Often fails to examine own attitudes to mental illness or to realize that attitudes are held		widespread; educates self
			0	Addresses and influences
				municipal, provincial, state or
				national governments and agencies
			0	Communicates effectively
			0	Creates strong family organization

## Beginning, Maintaining and Developing Family Self-Help, Support and Advocacy From Small Group to Large Organization

#### 1 Why Begin a Support Group?

#### 1.1 The Need - Coming to Terms with Schizophrenia

I didn't believe that this had happened to me. Mental Illness was the fate of poor, disadvantaged people, not me. Then I went to a support group meeting - I was amazed - there were families from all walks of life, many of them in circumstances similar to my own.

Inge. a mother

Being able to accept that a relative has schizophrenia takes time. People who have not experienced mental illness up close are embarrassed and fearful, just as the person with schizophrenia and his family are when it happens to them. They find it difficult to speak about the illness, because of their own emotions and because they are afraid of how people will react. They may also be the victims of their own prejudices about mental illness. Forced to examine their own feelings, they must take a critical look at their own values. Historically mental illness has been a reason for shame. Now that we know that mental disorders are described as chemical, sometimes genetic, disorders of the brain by the medical profession, there should be no reason for shame. Schizophrenia is an illness in the same way as is multiple sclerosis or cancer. Nevertheless, old perceptions and cultural belief systems die hard, and the family may have a great deal of difficulty admitting to themselves as well as to others that they are affected. Until they can do this, the burden will be even greater.

#### **Emotional and Practical Support**

People involved with psychotic illnesses note that the family, most often the primary care giver, is under enormous stress every day:

Personal stress is something that often goes unacknowledged. The sick person becomes a priority, and we forget our own needs. The day to day tasks involved in caring for a dependent - sudden crises, worry, financial problems, searching for community services, coping with bureaucracy, becoming an advocate, squeezing out precious moments for our other family members - depletes and robs us of our energy. Eventually we end up with stress exhaustion, and this can lead to depression, anxiety, burnout, and psychosomatic illnesses.

Elenor Smith, Alberta Schizophrenia Society

Families and health care professionals caution that the strain of having a relative with schizophrenia, or related disorder, can begin in the very early days, when the person's behaviour starts to deteriorate. Even before a diagnosis is made, families undergo unusual pressures coping with someone whose behaviour is becoming increasingly abnormal. After the illness is diagnosed it is entirely normal to have feelings of guilt, resentment, fear, anger, bitterness, shame and grief. The important thing is to learn to deal with these feelings.

Meeting with other families that share a similar experience has proven invaluable in easing the burden. There are support groups for families in many communities that were begun by and for families in need of help, and by professionals who recognise this need. They have been able to give each other great strength in dealing with their problems. Many groups have become more sophisticated and offer a wide range of services and programs to their members.