

# Schizophrenia Awareness Week 2004 Symposium

## **Suggested first stage of setting up a support group - taken from The History of the Mental Health Support Group of Tamworth and district**

by Joan Wakeford, Co-ordinator, Tamworth Support Group

The Mental Health Support Group of Tamworth and district will be 10 years old next year. Membership is open to anyone but mainly consists of carers and consumers. It has a small band of core members and a network of associate members who ring only when they need help and advice. Our members may live anywhere in the Health Area, which is larger than Tasmania. When the support group has been asked for help with a specific project our members have given many hours of voluntary work eg renovating accommodation for rural consumers.

The New England Health Area is writing policies for carer and consumer participation in evaluating mental health services. Members of the support group have been involved in all the early discussions. We have a presence in the community, and are often invited to speak at meetings. This seems to me to indicate that we have been successful, and our experience could help support groups in other areas, especially rural ones. It is a fact that support groups are the most helpful service available to carers, and a survey of 299 carers in Victoria rated their support group as 30% more helpful than any other service. If service providers are to give 'best practice' services, they must help to initiate support groups.

The following article is part of a paper that I gave, with another carer, at the NSW Rural Mental Health Conference in March this year.

### 1. Service providers make family support a focus for clinical work:

They initiate a family meeting by inviting carers who have leadership abilities, as well as a range of family members to discuss the advantages of setting up a support group. (Service providers are usually the only people to whom all these family members are known)  
An invitation does not breach confidentiality, it is a choice  
Services offer a venue and support for future meetings

### 2. Family members decide to start a support group. Leadership considerations:

- \* Rural people know their communities. Natural leaders in the group will select a steering committee, then advertise a public meeting, and elect an executive
- \* Sharing the leader's role between several people has many advantages
- \* Leaders will need to be sensitive to the feelings of their family members
- \* They will need to decide on membership eligibility
- \* Make self care a priority

### 3. Joining a "sponsor" group is valuable for leaders because sponsors will:

- \* Supply a leader's manual with relevant and comprehensive advice

- \* Give financial support eg tax deductibility for donations
- \* Extend Public Liability Insurance to members
- \* Visit the group and support it with experience and practical information

4. Confidentiality – members agree that matters discussed at meetings will not be shared outside the group. Members decide whether they will be available for contact between meetings, and if they will link with new families who need support between meetings.

5. Meeting procedures that allow all members to participate:

- \* “Problems” have a habit of overwhelming meeting procedure
- \* Shared leadership allows support to be given separately, while the meeting proceeds
- \* Have resources available to hand out when required
- \* It helps to have a clear understanding of the stages of support
- \* It is not helpful to send a family who are in the stage of needing information about mental illness to a support group where they may be confronted by worse case scenarios or hear people offload emotions
- \* Just as inappropriate is to recommend a programme about basics of mental illness to a family who is at the stage of needing long term emotional support

People who must network with the group by telephone because of distance can obtain information, have resources posted and link with individual members whenever possible.

### **Suggested second stage - remaining stable**

1. Members will change, but for numbers to remain viable:

- \* Advertise all meetings in every way possible, especially in the free press
- \* Focus on coping strategies for families
- \* Invite interesting speakers on relevant topics
- \* Ask the media to do articles and radio interviews about mental health support
- \* Plan projects chosen by the group and back them with action
- \* An advocates course or counsellor training is useful
- \* Hold some fun activities
- \* Set up a telephone support service and have contact details in directory
- \* Network with other support groups

2. Establish a good working relationship with area health services

- \* Keep current details of how to access services and a list of services for families
- \* Nominate for consumer and carer representative positions on policy and evaluation committees
- \* Ask services to notify the group of conferences or workshops, in or out of the area

3. Support family members in building a therapeutic alliance with treating clinicians

Family members need to keep in touch with clinicians to understand their role in treatment plans.

They also need to know that they have the right to give "information concerning family relationships and any matters relating to the mental state of the consumer to health service providers" (Mental health statements of rights and responsibilities 1991)

#### 4. Learn more and more about the mystery of mental illness - fighting stigma

- \* Invite professionals to be guest speakers on a range of topics
- \* Attend as many conferences or workshops as possible
- \* Get a list of mental health books from the local library and critique them
- \* Use the sponsoring body to recommend or pass on informative papers eg new research
- \* Share the classic texts eg Fuller Torrey, Xavier Amador, Ken Alexander
- \* Visit web sites eg Sane Australia, NSW Schizophrenia Fellowship
- \* Plan an educational forum for your area

Been There/ Done That.

What do we do now?            Look at the big picture:

- 1) Join a state body to represent consumers and carers, read the national & state policies for mental health service provision
- 2) Help other towns establish support groups
- 3) Lobby politicians for increased funding for MH Services
- 4) Sit on management committees for non - government MH Services
- 5) Visit services in other areas for good ideas
- 6) Join the World Federation for Mental Health

To conclude:

The MH Support Group of Tamworth and district has quietly achieved an amazing list of things when I think about it. In 2000 we organized a regional forum for 120 people, (mainly consumers and carers) to consult about the employment of advocates in the region. We turned our hands to sewing and made half a MH Standards Quilt, which is now travelling NSW. Once a week for 2 years, members have taken a large cane basket of snacks to sell in Banksia, the acute care ward.

Telephone support has been accessed by people from Queensland to Melbourne and west to Broken Hill. It has been one of our most effective ways of helping families and finding new members.

We have our 'Support Group' listed in the telephone directory.

Members of the support group are working on regional and State Mental Health committees. Hundreds of meetings have been attended. We are foundation members of Billabong Clubhouse.

Local people in the network have given hours of voluntary work to the hottest new project - accommodation owned by Billabong Clubhouse. A cottage has been transformed from a wreck to a charming guesthouse. Our group has recently been invited to assist several new support groups: there is a brand new support group in Gunnedah and a support group may

soon start in Manilla. We are planning closer connections with support groups in Narrabri and Armidale.

Perhaps a last quotation will explain what has kept our core members (described once to me as a 'bunch of burnt out old carers') committed to this support group for the last 8 years: "It is one of the most beautiful compensations of this life that no one can seriously help another without helping himself." (Charles Warner 1873)

Today we have added our story 'to the mounting body of evidence' that family support benefits consumers, carers, family members and service providers, and we have shown that it can happen in rural and remote areas, especially when services understand their role in helping families to come together in the first place.

I would be very happy to receive your feedback, or give further information. I can be contacted by email: [wakefordpj@optusnet.com.au](mailto:wakefordpj@optusnet.com.au) or by mail to Joan Wakeford, 64 Yarmouth Pde., Tamworth 2340.

#### References:

Born to Whinge by Kerry Cue 1988  
Moving FORWARD CD, Hunter Institute of Mental Health  
Family Education and Training, A program based on the work of Professor William McFarlane, adapted for Australia by Gordon Lambert and Margaret Leggatt  
Information in overhead from: "Mental Health Services for People in Crisis", A report to the Legislative Council & Legislative Assembly of Victoria by the Auditor General, 2002.

#### The classic texts:

Surviving Schizophrenia, a manual for families, consumers and providers. E. Fuller Torrey, MD.  
I am not sick, I don't need help! By Xavier Amador, PhD.  
Understanding and Coping with Schizophrenia, 14 principles for relatives. Ken Alexander.  
The Group Leader's Manual. NSW Schizophrenia Fellowship 2000.  
Working Together. A short, practical guide for consumers, family carers and mental health professionals to work together in collaboration and partnership. Margaret Leggatt 2002.  
Quotation from Charles Dudley Warner, 1873. American Essayist. (Group Leaders Manual).  
.....Joan Wakeford.