

***WORLD FELLOWSHIP FOR SCHIZOPHRENIA
AND ALLIED DISORDERS***



FAMILIES AS PARTNERS IN CARE
Guide to Professionals Doing Family Work
in Developing Countries

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124 Merton Street, Suite 507

Toronto, Ontario, M4S 2Z2, Canada

Phone: +1.416.961.2855; Fax: +1.416.961.1948

Email: info@world-schizophrenia.org

Website: www.world-schizophrenia.org

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FAMILIES AS PARTNERS IN CARE

**Guide to Professionals Doing Family Work
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This program has been adapted by WFSAD for work in developing countries from the work of Ian Falloon, M.D., with his permission. Prof. Falloon's "Integrated Mental Health Care" and "Optimal Treatment Project" are well known in the field.

INTRODUCTION:

Families as Partners in Care is based on research indicating that people with mental illness recover better when their families are part of the treatment team, and receive education, training and support in how to manage the illness. The burden for families is also reduced. FPC teaches family carers, friends and patients how to manage mental illnesses using the best possible treatment method; and shows how mental health workers can work together with family carers and patients. People read this booklet and then together plan the best way to solve problems and to achieve goals in their lives. People who are diagnosed with a mental illness will have a better recovery if we plan an integrated mental health care program.

INTEGRATED MENTAL HEALTH CARE PROGRAM:

This involves the following steps:

1. Form a **patient resource group** consisting of:
 - the mental health worker
 - family and friends
 - the patient
2. The **mental health worker** (the teacher) will:
 - assess symptoms and teach us about the mental disorder
 - explain the medication
 - help us cope with stresses in our lives by teaching us skills that make it easier to cope
 - encourage us to find new ways of handling difficult problems, and to practise these new methods of problem-solving
 - help us when we have crises in our lives
 - help us give each other rewards for all our efforts (even if sometimes, we fail to achieve our goals, we have at least made an effort)

The mental health worker attends the group meetings in the beginning, but as families and friends and patients learn to solve their own problems, the mental health worker need no longer come. Remember the teacher can help to improve our problem-solving skills, but cannot actually solve our problems. It must be agreed from the beginning , that taking drugs or alcohol, physical violence or other major disturbing behaviour is not allowed during the support group meetings.

3. The **resource group session** should last about one hour and meet at a regular time each week. Each session has these sections:
 - review of progress of treatment of illness
 - review of progress with solving problems
 - teaching specific skills to help achieve personal goals
 - how to use these skills in the next weeks

The program usually lasts about 10-12 weeks—thereafter meetings can be arranged when and if needed. Sessions may need to be shorter (and kept very simple) for people who remain seriously disabled and have difficulty with concentration

4. **Practicing new skills** in everyday life: Skills learned in the sessions must be used in everyday life. (If the sessions can be carried out in the house, this is better than learning skills in the hospital and then trying to use those skills at home).
5. **Assessment of the problems and goals** of people and their family carers. Resource group members need to:
 - understand the mental disorder and other health problems that are present now or that could develop.
 - understand each other's real-life problems
 - understand what strengths and weaknesses we have
 - use all the resources we can find to develop a good treatment plan that will reduce the possibility of future problems

RESOURCE GROUP MEETINGS:

The first resource group meetings are mainly about understanding and learning to manage the illness. When resource group members feel they understand the illness and are more confident in its management, then resource group meetings focus more on solving life problems and achieving personal goals.

DIAGNOSIS

Ask the following questions to help with the diagnosis of the mental disorder:

- How has your sleep been in the past week? Any difficulties getting to sleep? Waking early?
- Have you lost your appetite recently? Weight loss of 2 or more kilograms? Dieting?
- Have you experienced loss of energy or interests recently?

- Have you been worrying a lot about everyday problems?
- Have you had difficulty concentrating on reading or watching T.V? Have you been more forgetful than usual?
- How do you see your future? Do you ever feel that life is not worth living? Have you felt you would like to end it all?
- Have you any special habits, like checking or cleaning more than people say is necessary?
- Do you ever have attacks of your heart beating fast, sweating, shaking or dizziness accompanied by feelings of intense fear?
- Has anybody commented that your speech has become odd or difficult to understand?
- Have you had the experience of hearing peoples' voices speaking when nobody seems to be around at the time?

SPECIAL MENTAL HEALTH CONSULTATION

Any positive responses to the above questions that are not explained by a general health problem, must be discussed with a specialist mental health worker. A comprehensive assessment often requires several hours of detailed questioning. This will include the following steps:

1. **Background information:** Information that is helpful includes:
 - age, male/female, marital status
 - household size
 - education/jobs and training – past and present
 - medical and mental health background
 - health problems of resource group members
 - stress factors
 - drug and alcohol intake
2. **Current symptoms of mental disorders:** A standardized interview is made to clarify which mental health symptoms are present and what is the most likely diagnosis. Once it is clear what type of mental disorder is present, more questions may be asked to find out the severity of the disorder. Mental health professionals will use rating scales with which they have been specially trained.
3. **General and mental health** of resource group members: When members of our resource group are also suspected of having a mental disorder, the same assessments may be done for them as well. Families and close friends can give additional background information and help us clarify the exact nature of the mental disorders and risk factors.

GENERAL AND MENTAL HEALTH PROFILE

Name of person interviewed: _____

Male

Female

Marital status: _____

Relationship to patient: _____

Educational background (highest level): _____

Work background: _____

Medical/mental health treatment:

Current: _____

Past: _____

Family background of mental disorders: _____

Relevant stress factors: _____

CAUSES OF SYMPTOMS

In order to find out what causes the symptoms to appear, or makes the symptoms worse, first list the symptoms that prevent adequate functioning by the patient—i.e., the EXACT symptom. This means describing the exact behaviour rather than the thoughts and feelings the behaviour produces. For example, Mary's 'feelings of panic' are better described as 'an increased heartbeat, sweating hands and a tight feeling in the chest.'

- How often does the symptom occur?
- How intense is it?
- When did it start?
- Have any changes occurred over time as a result of treatment?

Try to discover what was happening just before the problem symptoms began. In other words, what caused the symptoms to appear? Now, if the causes continue, so will the problem. For example, if being too close to people causes anxiety, continuing to be in people's company will mean we stay anxious. List behaviour that produces the symptom. List things we can do to make the symptom less likely to occur.

MOTIVATION TO CHANGE

It is important to understand that some people may find living with the problems easier than solving them. Special plans will need to be made to overcome this added difficulty. Problem-solving we have taught ourselves: Perhaps we have already found some good ways to reduce symptoms. It is important to recognize these and to encourage ourselves to use them even more effectively. Finally, list all the people (family, friends, professionals) who might help us prevent symptoms from happening again.

UNDERSTANDING THE MENTAL DISORDER

It is important that everyone understands and agrees on the nature of the mental disorder, so that we all work together towards the same goals for recovery. Resource group members find answers to the following questions:

<p>What is the patient's disorder called? _____</p> <p>What do you think has caused the disorder? _____</p> <p>What makes the disorder worse? _____</p> <p>What makes the disorder better? _____</p> <p>What do you think will happen to the disorder in the future? _____</p> <p>What treatment is the patient having at present? Medication? _____</p> <p>Help through talking to the patient? _____</p> <p>What benefits have you noticed? _____</p> <p>Is any of the treatment causing problems? _____</p> <p>Does the patient cooperate with treatment? _____</p> <p>Are you satisfied with the patient's treatment? _____</p>
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STRESS AND COPING WITH THE DISORDER

Problems that have arisen for families and friends as a result of the mental disorder are now discussed. The manner in which we cope with these problems is noted. People with mental disorders and members of their resource group may have quite different problems coping with the disorder and quite different stress levels.

<p>What are the main difficulties caused by the patient's disorder? _____</p> <p>What do we do to cope with these difficulties? (List effective and ineffective ways of coping)? _____</p> <p>In the last three months, how much stress has there been in our lives that has been caused by the patient's disorder? _____</p>
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IMPROVING OUR LIFESTYLE

Living with mental illness creates many burdens. It is important that we find ways to improve our lifestyle, so that unhappiness and frustration can be lessened. The following questions need to be answered by the patient, but the questions can also be answered by family carers about themselves, particularly if their caring role is causing frustration.

<p>Who would you like to discuss your personal goals and problems with? _____</p> <p>_____</p>
<p>What activities, places and people do you find unpleasant and try to avoid? _____</p> <p>_____</p>

SETTING PERSONAL GOALS

At this point , we can try to choose one or two goals that we think we could achieve during the next three to six months. If we achieve these goals we hope that they will make a difference in our everyday enjoyment of life. Choose goals that will not be too difficult to achieve, for example, those that will not:

- cost money
- require special skills
- be too complicated
- require too many resources

Choose goals that will clearly make our everyday life more enjoyable—contact a friend, or do something we enjoy. Complicated or difficult goals may be broken down into several small steps. For instance, if we have not had a job for some time, we may break that goal down into:

- deciding on the type of job we would like
- getting trained in any skills we would need
- finding vacancies for that work in the local area
- going for interviews and accepting a suitable position
- starting the job and getting settled in

ACTIVITIES:	
What activities do you spend most time doing?	How would you rather spend your time?
1. _____	1. _____
2. _____	2. _____
3. _____	3. _____

LOCATIONS:	
Where do you spend most of your time?	Where would you rather spend your time?
1. _____	1. _____
2. _____	2. _____
3. _____	3. _____

PEOPLE:	
Who do you spend most of your time with?	Who would you like to spend most of your time with?
1. _____	1. _____
2. _____	2. _____
3. _____	3. _____

GOALS:
<p>Goal 1: Describe exactly what we will be doing when we have achieved this goal: _____ Problems encountered or anticipated: _____ _____ Who is offering support? _____</p>
<p>Goal 2: Describe exactly what we will be doing when we have achieved this goal: _____ Problems encountered or anticipated: _____ _____ Who is offering support? _____</p>

OTHER PROBLEMS

There are usually a wide range of problems created not only by the mental illness, but by other circumstances in peoples' lives. It is a good idea to list these, so that we understand the pressures that people are having to cope with.

Are there other problems in our life at present?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Work	_____	
Housing	_____	
Finances	_____	
Education	_____	
Leisure/recreation	_____	
Friends	_____	
Sexual problems	_____	
Family relationships	_____	
Child care	_____	
Cultural conflicts	_____	
Alcohol/drugs	_____	
Caring for self	_____	
Other	_____	

FINDING SOMEONE TO HELP ME RECOVER AND STAY WELL

People who have major health problems recover more rapidly and then stay well longer when they have one or more friends or family members who are around to help them solve problems and deal with the stress in their lives. 'Ideal' helpers are:

- available at all times
- make you feel relaxed when you talk about your problems
- can meet with you regularly
- have no big problems of their own
- know about your mental disorder, but are not worried by it

Don't worry if you cannot think of anyone who has all these features. These are some of the points to consider when choosing your helper. Make a list of the people who might be good helpers.

1. _____
2. _____
3. _____

Go down this list and say what we think would be the main good points and main bad points about each person as a helper. Then decide who we will ask first. How can I ask somebody to help me? Asking somebody to help us is difficult. So we need to make a very careful plan of how to do it and how to cope with the difficult steps. What we have decided on may be a little difficult for us and for most people. Asking people to help us is something very few of us have done before. Some steps that many people have found difficult include:

- making phone calls
- arranging a meeting
- talking about the mental illness
- what to do when the person says 'no'

What are the difficult steps in our plan?

On page 11 you will find model "invitations" to the person or persons that we would like to help us (or the person we are helping) recover from mental illness. If the helper cannot read or write, that is difficult. It means we will have to talk to the person face-to-face, which can sometimes be embarrassing.

SOLVING PROBLEMS & ACHIEVING GOALS

Teaching people to solve problems improves the mental and possibly the physical health of patients and their carers. This enables people to manage problems in their lives with less stress and with some enjoyment. We have learnt to ask people to help us. Now, we shall sit together, discuss a problem and plan how to solve it using this 6-step process.

When we have had practice with problem-solving, we will find that we are able to tackle all sorts of very difficult issues without too much stress if we follow the steps. The leader of our resource group will make sure that everyone follows the steps, and keeps to the rules. Our secretary keeps notes on the problem-solving and goal achievement worksheets. The worksheet on page 12 lists the six steps. A copy is given to the patient so that the patient and his helpers can remember what has been planned.

USING ACTIVE LISTENING

Be clear about our problems and goals. It is not always easy to define what worries us, or what goals we would like to achieve. If we sit down and talk these things over with some good friends or our family they can help us see the problem or goal more clearly. Talking things over together so they become clearer is called active listening. Active listening helps people to make clear, realistic goals, rather than goals that are impossible to achieve. Clarifying problems and goals with active listening:

- Look at speaker. Look interested in what they are saying
- Listen carefully to what they say. Reduce distraction from noise, TV, young children.
- Ask questions to make it clear exactly what is the main problem or goal.

- Check that we have understood the point clearly by telling the person what we have thought he or she was saying. Ask if that is correct. For example: "So you would like to make a friend with somebody who likes sport? Have I got that right?" You are upset that you have not got a job at the moment? Is that the main problem?"

Now it's time to practice problem-solving and active listening in our resource group

- Each person suggests a problem or goal they would like to become clearer about.
- For 5 minutes everyone else asks many questions to help to uncover exactly what that problem or goal is.
- Then tell each other what we liked about the way we all used the steps of active listening.
- Once we have done that, we may have time to use the 6-step problem-solving worksheet to solve one of the problems that we have specified very clearly.

HOW TO ENCOURAGE PEOPLE TO DO MORE THINGS THAT PLEASE US

Telling somebody that they are doing something that pleases us is one of the simplest and most successful ways of encouraging that person to do more of that particular activity. It is also a great way to deal with everyday stresses. Each day people do hundreds of things that make our lives more satisfying and enjoyable. Many of these things are so routine that we forget to tell the person that they please us a little. Ask yourself how you feel when somebody tells you that they are pleased with something you have done.

GUIDELINES FOR EXPRESSING PLEASANT FEELINGS

1. Look at the person and speak in a friendly way (smile, shake hands etc.)
2. Tell the person exactly what things they did that pleased us.
3. Tell the person exactly how it made us feel when they did that (I was pleased/ happy/ It was nice of you etc.)
4. Practice this strategy every day to get into the habit of using it. Use it at the beginning of the next teaching session.

NOTES

INVITATION TO HELPER

Dear _____:

I would be very pleased if you could help me with my mental health treatment program. To get the best results from this program, I need to take medication regularly. I have been told that I can double the benefits that the best medicine can achieve if I can find a person to help me with the stress I have in my life. My disorder is likely to get worse when I have high, or even low, stress that is not sorted out quickly. If you are so kind as to agree to help me with my program for recovery from my mental disorder it would be best if you and I could meet at regular times at least once or twice a week. At these times we would talk about problems and plans, as well as other things. Some of these meetings would be with people from the mental health service.

They will teach us both to become experts at dealing with stress in our lives. Although this will help me recover from my illness and get on with my life, I have been told that it might help you in some ways as well.

The name and phone number of my teacher at the mental health service is:

He/she would like to arrange to meet with us both to talk more about this and to answer any questions that you might have.

INVITATION FROM MENTAL HEALTH WORKER

Dear _____:

My name is _____ . I am working with _____ to develop a program to help him/her recover from a mental disorder. I am extremely happy that you are interested in helping us with this program. I would be very grateful if you would provide me with your full name, address and phone number so that we can arrange to meet to talk about how we might all work together.

Name: _____

Address: _____

Telephone: _____

Best Times to Meet: _____

Looking forward to meeting you,

PROBLEM-SOLVING WORKSHEET

Step 1: What exactly is the problem or goal?

Talk about the problem or goal until we can write down exactly what it is. Break a big problem or goal into smaller parts. Start with a simple problem or goal before moving on to difficult ones.

Step 2: List all possible solutions.

Make a list of all ideas, even 'bad' or 'silly' suggestions. Get everyone to suggest something. Do not talk about whether ideas are good or bad at this stage.

Step 3: Discuss the advantages and disadvantages.

Get our group to say what we think are the main advantages and disadvantages of each suggestion.

Step 4: Choose the most practical suggestion

Choose the solution that fits the resources that are available—time, money, skills.

Step 5: Plan exactly how to carry out the solution

Organize the resources we need. Consider how to cope with difficult steps.

Step 6: Review progress in carrying out plan

Praise all the efforts people have made. Review progress on each step. Change the plan. Try another solution. Continue problem-solving until our problem is resolved or our goal is achieved.
