

World Fellowship for Schizophrenia and Allied Disorders

Third Quarter 2005

Changing Roles in Family Support

by Diane Froggatt

“Adolescent” or “rebellious” are two words families often use to describe their relatives during the long battle before they realize that something is terribly wrong. What they are experiencing is much more than “adolescent behaviour.” They may finally seek help for something that is too big to handle alone. They dread what they are going to find out and the age-old bugaboo, stigma, influences their behaviour. Not quite able to accept what they fear the most, they may go first to their pastor/minister or to the local healer. When they find no remedy they confide in their best friends and lastly seek medical help. “I thought what he had was a nervous breakdown,” said one father, “that it would be over in a matter of a few weeks and we could continue where we had left off, with him going back to college, but it didn’t turn out like that.”

It is only recently with the establishment of “First Episode” clinics or “Early Intervention” services in some major centres that some families and their unwell relatives have been given the opportunity to understand what is happening to them and to get the support and help so necessary to their well being in the early stages. These services use up-to-date comprehensive care methods and welcome the input of families. They often offer information sessions and/or introduce their clients to self-help organizations. In places where early intervention services do not exist – and they are the majority – it can be a matter of years before families find appropriate continuing care, support and knowledge. That’s why it is so important that family and consumer self-help become better known and used.

I asked people involved with family self-help organizations how long people had been without self-help before finding their services. The time varied from two years to ten years or more. Those who arrived early for help retained high expectations for their relatives and did not expect to give these up. For those who arrived later in the illness, there had been a lot of frustration and disappointment before realizing they had to change their expectations and move along a different path. In some cases they had not had any kind of moral or social support prior to arriving at self-help.

Family support organizations embrace all the families that come to them. And now, with changes in treatment and increased hope, there are signs that people are coming much earlier. Support groups tend to offer “one size fits all” services and this can be a problem when helping people in different stages of caring. In addition, people with mental disorders are not a homogenous group either in their personalities or symptoms of disease. These factors need to be considered when arranging family and consumer support.

Early Years

What are the issues that surround people in the early years of illness? Stigma is an extraordinarily important challenge for everyone and it is very real. It can influence people’s actions and decisions and is a great barrier to obtaining medical treatment, to getting support and to a continuing healthy life. “The intense disbelief that people feel when given a diagnosis of mental disorder matches the similar disbelief of people who are told they have

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This newsletter is an international bulletin published by the World Fellowship for Schizophrenia and Allied Disorders (WFSAD). Our goal is to provide information to the world self-help movement for schizophrenia and allied disorders that includes national local organizations, individuals coping with illness and friends and professionals

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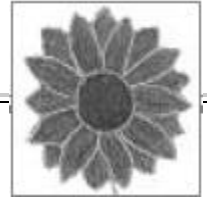
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Changing Roles in Family Support (Continued)

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cancer”, said Dr. Joyce Burland, founder of the National Alliance for the Mentally Ill (NAMI) Family to Family program in the U.S. It is quite common for people to think they have been given the wrong diagnosis. With cancer they might say incredible things like: “Those aren’t my x-rays, the doctor is wrong – I’ll go to another doctor.” Such denial is similar with mental illness. When faced eventually with the reality, people exhibit what Burland calls “counter-intuitive” behaviour. They respond by shutting down. They are paralysed by their own confusion and are unable to act, hoping against hope that the illness will go away. At this point it can be very difficult for those offering services to give traditional kinds of support. “I was in a complete daze,” said one woman. “The Society gave me a bunch of booklets which I didn’t even realize I had till a month later.”

For these families a separate support group will mean a voyage of self-discovery for everyone. They will need pragmatic, no-nonsense help to deal with day-to-day current issues. They may need some information about the illness they are dealing with, but in-depth learning will come later. The sort of questions asked will reflect immediate concerns: how long will s/he be sick; is the behaviour totally related to illness; will s/he be able to continue going to college/work; will medicines more or less cure him/her; was it something we did that brought this on? As well as getting answers to these and similar questions, they will be given reassurance and will learn to understand that their reactions are quite normal, that they can emerge from the other side of their trauma. Too much information too soon, however, is not recommended.

Middle Years

For families who have passed the initial stage of shock there will be several areas of focus. Families might not be expecting that their relative would continue to live with them. They might also not realize that living with someone with mental illness takes patience and commitment as well as unconditional love. Physical and mental accommodations have to be made that will affect everyone in the household. Just as accommodations must be made for a physical disability – widening doors, creating ramps, etc., so such changes have to be made for a person who suffers symptoms of schizophrenia or other mental disorder. Families often need to be taught how to do this.

It is usually in the middle years that families feel they need to “give back” to their self-help organization by becoming politically or socially active. At this time they benefit from extra knowledge about research, services and the health system they live under.

Later Years

A later stage of family support surrounds those persons whose relatives are either still unwell after several years or who still need a measure of support in their daily lives. Dr. Diane Marsh, a researcher in family work in the U.S., noticed how resilient families could be even under these difficult circumstances. Said one family in her survey: “It is gratifying to witness our son’s courage as he deals with his illness. Family education enabled us to be a help rather than a hindrance for him. It has been gratifying to be a part of his process toward recovery and to be able to talk with him about his illness.”

These families ask the question “What will happen when I’m gone?” They encourage younger members of the family to take on the caring role and they try to secure the financial future of their sick relative through legacies, life insurance policies, trusts and the like. If they have not sought appropriate housing arrangements for their relative prior to this point, they are anxious to do so now.

They also want to keep abreast of what’s available in the treatment of the illness in case their relative can benefit from a new medication or a psychosocial or occupational service that may bring their relative toward better functioning and a better life style.

Many people at this stage of their loved one’s illness become the backbone of their self-help organization. Confident of their experience, they feel proud in the role they can play both in making life better for their relative and for their community. They are willing to work with psychiatric personnel and politicians to obtain improved care for the mentally ill and this work is their personal support.

Family/Consumer Support

For well-established associations it is productive to offer support groups for families in these different stages of their relative’s illness. However, to give several levels of support may be difficult for a self-help organization with limited resources.

If an organization can develop training materials for use in a variety of situations (and it probably has begun this through the development of educational materials in pamphlet form or on a website), it may be preferable to offer support in a formal way, giving several courses a year, each for different phases of experience. This has the benefit of freeing up each course to focus on the specific issues. It also has the benefit of serving families throughout their caring career.

To develop this kind of support one needs experienced volun-

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The Schizophrenia Patient Outcomes Research Team (PORT): Updated Treatment Recommendations 2003

In 1992 the U.S. Agency for Health Care Policy and Research and the National Institute of Mental Health established the **Patient Outcomes Research Team (PORT)** for schizophrenia at the University of Maryland School of Medicine and the Johns Hopkins University School of Public Health. The prime objective of the PORT is to develop recommendations for the treatment of persons with schizophrenia based on a synthesis of the best scientific evidence, with the ultimate goal of improving the quality and cost-effectiveness of care for persons with this diagnosis. The PORT recommendations are based on substantial scientific evidence and reflect what is known from well-controlled research. The first set of PORT treatment recommendations were issued in 1998. Five years later an updated set of recommendations were issued and published in 2004 (Report in the *Schizophrenia Bulletin*, Vol. 30, No. 2). We reproduce the Abstract from the above article and follow it with the updated treatment recommendations without the comments or rationale published in the journal.

Abstract

Since publication of the original PORT treatment recommendations in 1998, considerable scientific advances have occurred in our knowledge about how to help persons with schizophrenia. Today an even stronger body of research supports the scientific basis of treatment. This evidence, taken in its entirety, points to the value of treatment approaches combining medications with psychosocial treatments, including psychological interventions, family interventions, supported employment, assertive community treatment and skills training. The most significant advances lie in the increased options for pharmacotherapy, with the introduction of second generation antipsychotic medications, and greater confidence and specificity in the application of psychosocial interventions. Currently available treatment technologies, when appropriately applied and accessible, should provide most patients with significant relief from psychotic symptoms and improved opportunities to lead more fulfilling lives in the community. Nonetheless, major challenges remain, including the need for (1) better knowledge about the underlying etiologies of the neurocognitive impairments and deficit symptoms that account for much of the disability still associated with schizophrenia; (2) treatments that more directly address functional impairments and that promote recovery; and (3) approaches that facilitate access to scientifically based treatments for patients, the vast majority of whom currently do not have such access.

I. Psychopharmacologic Treatment Recommendations

A. Treatment of Acute Positive Symptoms in Treatment-Responsive Patients

Recommendation 1. Acute Antipsychotic Treatment

Antipsychotic medications other than clozapine should be used as the first line treatment to reduce positive psychotic symptoms for persons with multi-episode schizophrenia who are experiencing an acute exacerbation of their illness.

Recommendation 2. Acute Antipsychotic Medication Dose

The daily dosage of first generation antipsychotic medications for an acute symptom episode should be in the range of 300 to 1,000 chlorpromazine (CPZ) or 5 to 20 haloperidol (HPL) equivalents. The daily dosage of second generation antipsychotic medications for an acute symptom episode should be 10 to 30 mg for aripiprazole, 10 to 20 mg for olanzapine, 300 to 750 mg for quetiapine, 2 to 8 mg for risperidone, and 120 to 160 mg for ziprasidone (for all except risperidone, there was insufficient research to determine the upper effective dose limit). Reasons for dosages outside of this range should be documented. Treatment trials should be 4 to 6 weeks; if unsuccessful, do not discount the efficacy of the drug. [Ed. Note: A table showing dosages appeared in the last issue of this newsletter, 2-2005.]

Recommendation 3. Acute Antipsychotic Medication Dose in First Episode Patients

Persons experiencing their first acute positive symptom episode should be treated with an antipsychotic medication other than clozapine, but dosages should be started on the lower end of the recommended range (conventional antipsychotics: 300 to 500 mg CPZ or 5 to 10 HPL equivalents per day; second generation antipsychotics: lower half or recommended dosage range).

B. Maintenance Pharmacotherapy in Treatment-Responsive Patients

Recommendation 4. Maintenance Antipsychotic Medication Treatment

Persons who experience acute and sustained symptom relief with antipsychotic medication should continue to receive antipsychotic medication in order to reduce the risk of relapse or worsening of positive symptoms.

Recommendation 5. Maintenance Antipsychotic Medication Dose

The maintenance dosage for aripiprazole, olanzapine, quetiapine, risperidone, and ziprasidone should be the dose found to be effective for reducing positive psychotic symptoms in the acute phase of treatment. The maintenance dosage for conventional antipsychotic medications should be in the range of 300 to 600 CPZ or 5 to 12 HPL equivalents (oral or depot) per day. Reasons for dosages outside of this range should be documented.

Recommendation 6. Long-Acting Antipsychotic Medication Maintenance Treatment

Long-acting injectable antipsychotic medication maintenance treatment should be available and considered for persons who have a history of frequent relapse on oral medication, or a history of problems with adherence on oral medication, or who prefer the long-acting injectable depot regimen.

Recommendation 7. Targeted, Intermittent Antipsychotic Medication Maintenance Strategies

Targeted, intermittent antipsychotic medication dosage maintenance strategies should not be used routinely in lieu of continuous dosage regimens because of the increased risk of symptom worsening or relapse. These strategies may be considered for patients who refuse continuous maintenance treatment or for whom some other contraindication to continuous maintenance treatment exists (e.g., intolerance to the side effects of antipsychotic medications).

C. Treatment of Positive Psychotic Symptoms in Treatment-Resistant Schizophrenia**Recommendation 8. Clozapine in Treatment-Resistant Schizophrenia**

Clozapine should be used in patients with schizophrenia who experience persistent and clinically significant positive symptoms in spite of adequate treatment with other antipsychotic agents. Exceptions include patients who cannot receive clozapine because of histories of blood dyscrasia or cardiac arrhythmias. Lack of response to previous antipsychotic trials is defined by persistent positive symptoms after at least two adequate trials of antipsychotic agents, including at least one second generation agent. An adequate clozapine trial should last at least 8 weeks at a dosage from 300 to 800 mg per day. Dosages should reflect the lowest possible effective dose. If a patient does not respond to a dosage of 600 mg/day, a blood level should be obtained. If the blood level is less than 350 ng/mg, then the dosage should be slowly increased to 800 mg to the extent that side effects are tolerated. If effective, clozapine should be continued as maintenance therapy.

D. Pharmacotherapy for Other symptom and Functional Domains**Recommendation 9. Clozapine for Hostility**

Clozapine should be used in patients with treatment-resistant schizophrenia who present with persistent symptoms of hostility and/or display persistent violent behaviors.

Recommendation 10. Clozapine for Suicidality

A trial of clozapine should be considered for patients with schizophrenia who exhibit marked and persistent suicidal thoughts or behaviors.

Recommendation 11. Clozapine for neuroleptic malignant syndrome, tardive dystonia, and tardive dyskinesia

A trial of clozapine should be offered to patients who require antipsychotic therapy but who experience neuroleptic malignant syndrome (NMS), persistent dystonia, or severe or very distressing tardive dyskinesia (TD) when prescribed other antipsychotic agents.

E. General Psychopharmacologic Treatment Recommendations**Recommendation 12. Monitoring Antipsychotic Medication Plasma Levels**

Monitoring antipsychotic medication plasma levels is indicated in the following circumstances: (1) when patients fail to respond to what is usually an adequate dose; (2) in the very young, the elderly, and the medically compromised, in whom drug pharmacokinetics may be significantly altered; (3) when antipsychotic drugs are combined with other drugs that may affect their pharmacokinetics; (4) when medication nonadherence is suspected or to monitor adherence; and (5) when it is difficult for the clinician to discriminate drug side effects—particularly akathisia or akinesia—from symptoms of schizophrenia such as agitation or negative symptoms (e.g., a high blood level might be associated with increased adverse effects). See Recommendation 8 for monitoring clozapine plasma levels.

Recommendation 13. Prophylactic Antiparkinson Medications

In patients treated with first generation antipsychotic agents, prophylactic use of antiparkinson agents to reduce the incidence of extrapyramidal side effects should be determined on a case-by-case basis, taking into account patient and physician preferences, prior individual history of extrapyramidal side effects, characteristics of the antipsychotic medication prescribed, and other risk factors for

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SPECIAL FEATURE

PORT Recommendations

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both extrapyramidal side effects and anticholinergic side effects. The effectiveness of and continued need for antiparkinson agents should be assessed in an ongoing fashion. The use of prophylactic antiparkinson agents in patients treated with second generation antipsychotic medications is not warranted.

F. Adjunctive Pharmacotherapies

Recommendation 14. Antidepressants

Persons with schizophrenia who experience an episode of depression, despite an adequate reduction in positive psychotic symptoms with antipsychotic therapy, should receive a trial of an antidepressant. The reasons for the absence of an intervention for appropriate patients should be documented.

II Psychosocial Treatment Recommendations

Recommendation 15. Family Interventions

Persons with schizophrenia and their families who have ongoing contact with each other should be offered a family intervention, the key element of which include a duration of at least 9 months, illness education, crisis intervention, emotional support, and training in how to cope with illness symptoms and related problems.

Recommendation 16. Supported Employment

Persons with schizophrenia who have the goal of employment should be offered supported employment, the key elements of which include individualized job development, rapid placement emphasizing competitive employment, ongoing job support, and integration of vocational mental health services.

Recommendation 17. Assertive Community Treatment

Systems of care serving persons with schizophrenia should include a program of assertive community treatment (ACT). This intervention should be provided to individuals who have any of the following characteristics: high risk of repeated hospitalizations, difficulty remaining in traditional services, or recent homelessness. The key elements of ACT include a multidisciplinary team (including a psychiatrist), a shared caseload among team members, direct service provision by team members, a high frequency of patient contact, low patient-to-staff ratios, and outreach to patients in the community.

Recommendation 18. Skills Training

Persons with schizophrenia who have skill deficits such as problems with social skills or activities of daily living should be offered skills training. The key elements of this intervention include behaviorally based instruction, modeling, corrective feedback, and contingent

social reinforcement. Clinic-based skills training should be supplemented with practice and training in the individual's day-to-day environment.

Recommendation 19. Cognitive Behaviorally Oriented Psychotherapy

Persons with schizophrenia who have residual psychotic symptoms while receiving adequate pharmacotherapy should be offered adjunctive cognitive behaviorally oriented psychotherapy. The key elements of the intervention include a shared understanding of the illness between the patient and therapist, the identification of target symptoms and the development of specific cognitive and behavioral strategies to cope with these symptoms.

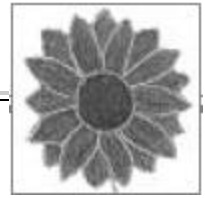
Recommendation 20. Token Economy Interventions

Systems of care that deliver long-term inpatient or residential care should provide a behavioral intervention based on social learning principles. The key elements of this intervention, often referred to as a token economy, are contingent positive reinforcement for clearly defined target behaviors, an individualized treatment approach, and the avoidance of punishing consequences.

In the Discussion section of the report the authors (Anthony F. Lehman et al.) state:

"Many of the original messages of the first PORT recommendations remain in this new set of recommendations. It is even more evident now that for the vast majority of patients, treatment must combine optimal pharmacotherapy with targeted psychosocial interventions. There are many more options for optimizing pharmacotherapy than in the past, and we should be well beyond the era when patients have to accept enduring unpleasant side effects in order to have fewer symptoms. Furthermore, for patients with residual symptoms, evidence-based psychosocial treatment options now exist and need to be applied in a targeted manner. ...

"The PORT treatment recommendations are designed to function as quality of care indicators that can be operationalized for purposes of evaluating patterns of treatment practices and quality of care research. They are not designed to provide a comprehensive discussion of treatment – in contrast, for example, to the American Psychiatric Association guidelines. They also do not cover pharmacotherapy in the depth provided by such guidelines as the Mount Sinai Conference on the Pharmacotherapy of Schizophrenia (Marder et al. 2002) or the Texas Medication Algorithm Project (Miller et al. 1999). Finally, certain clinically important topics, such as comorbid medical and substance use disorders, are not covered at all because, while of high clinical relevance, they are not central to the treatment of schizophrenia per se."



Let Us Try and See

Years ago while groping through a confusing labyrinth of mental illness, Anil Vartak of Pune, India, began writing a diary. Through his writing, he explored various strategies that eventually helped restore his health.

Details of these strategies are now offered in a booklet called *Let Us Try and See ... Personal Strategies for Mental Health*. It is available through the Schizophrenic Awareness Association located in Pune, India. See the entire booklet at http://www.schizophrenia.org.in/Let_Us_Try_And_See.doc. Here are highlights of Anil's strategies:

Writing a diary – Regularly recording emotions, thoughts and feelings in a diary can help dissipate negative thoughts and reduce stress. A diary also gives us the opportunity to reflect on how we and others handle the various situations encountered in life, and honestly explore what we could do better.

Make friends with your illness – If we hate our illness, we eventually will hate ourselves, especially if we have a long-term, chronic condition. Accepting that we have an illness, and that no one is to blame, can go a long way toward reducing inner turmoil.

Join a self-help group – A self-help group can provide a safe space where we can share experiences and interact with others who have the same illness, without fear of judgment or stigma. A self-help group can also offer guidance and a fresh perspective on the issues we are facing.

At first, things improve in bits – Minimize frustration and discouragement by recognizing that it will take time to improve. Do not overlook the importance of simple steps in the right direction.

Complete the tasks at hand – Performing tasks is a necessary part of life. Some tips to help us regain our confidence in completing tasks include keeping it simple, and making sure before we even start that we can complete the task in a short time. Avoiding comparisons and seeking help from others may also help us complete tasks.

Others have limitations – We can fall into a cycle of suffering perpetuated by our anger towards those who do not cooperate fully. Or we can recognize that others in our lives may never really understand what our illness is like. At the same time, we should not assume that everyone else is totally healthy, balanced and at peace.

Keep occupied – By deciding whole-heartedly to do whatever work comes to us when we are recovering is an important step in our development. It can bring peace of mind as well as provide a stepping stone to relearning the skills needed to do the work.

Eat and exercise regularly – Maintaining physical well-being through regular exercise and good diet provides support for mental and emotional rebuilding.

Regular medication is a must – If we want the overall outcome of our recovery efforts to be positive, then we should take the necessary medicines willingly. If the long duration of taking a medication is troubling to you, try to think of other health conditions that require long-term medication.

Don't stop medication abruptly – By helping to control the symptoms of an illness, medication provides background support for one's recovery. Lack of obvious results, however, may make an ill person or a caregiver rethink the necessity of the medication. Cultivate an attitude of thinking that this branch of medicine has scientific roots, and other people do benefit – so will I. Discuss your medication with your doctor and even seek another opinion.

Progress is not dosage-related – If the number of medicines or the dosage is reduced, we tend to think we are improving. On the other hand, an increase in the dosage can send us into a panic. Try to avoid reading meanings into the amount of medication we are taking by focusing on our psychological state and our efforts to sustain emotional balance and be at peace.

Mental illness and heredity – We worry that the illness we are suffering will be passed on to our children. Recognize that many illnesses – diabetes, heart disease, certain blood disorders – are more clearly hereditary than mental illness. The stigma against mental illness in society at large may be feeding our fears. While heredity may increase vulnerability to mental illness, you can give your children an example of good habits and what can be achieved through self effort.

Learn to face difficulties – Deep and lasting changes come from the heart, and demand effort and courage from us. In taking steps to solve problems, one discovers new undreamed-of resources within one's self that light up and clear the way towards recovery.

Rediscover your lost passions – Instead of feeling depressed about what one lacks, make a plan for regaining lost skills. For example, we may find interacting with peers difficult after a long illness. We could start regaining our confidence by interacting with children or even memorizing stories or jokes and telling them to friends when we have a chance.

Never give up – While recovering from a mental illness we have to constantly relearn the skills of compromise and adjustment. We have to reevaluate our decisions and expectations.



U.K. "Partners in Care" Campaign Resources

"Partners in Care," a joint campaign in England between the Royal College of Psychiatrists and The Princess Royal Trust for Carers, has produced several booklets for carers, including the following:

Carers and confidentiality in mental health – this booklet highlights confidentiality issues that arise between mental health professionals and carers of adults with mental health problems. Some of the issues are described, together with examples of good practice that may help address them.

Examples of the problems discussed include:

- Ethical and legal obligations
- Consent
- Barriers to sharing information

The booklet also includes a "good practice checklist" as follows:

1) Carers are given verbal and written factual information about:

- The mental health diagnosis
- What behaviour is likely to occur and how to manage it
- Medications – benefits and possible side effects
- Local in-patient and community services
- The Care Program Approach (CPA)
- Local and national support groups

2) Carers are helped to understand:

- The present situation
- Any confidentiality restrictions requested by the patient
- The patient's treatment plan and its aims
- Any written care plan, crisis plan or recovery program
- The role of each professional involved in the patient's care
- How to access help, including out-of-hours services

3) Carers are given:

- The opportunity to see a professional on their own
- The right to their own confidentiality when talking to a professional, unless disclosure is essential to the patient's care
- Encouragement to feel a valued member of the care team
- Confidence to voice their views and any concerns they may have
- Emotional and practical support
- An assessment of their own needs with their own written care plan (i.e., if the patient has a serious mental illness or learning disability)

Other publications produced by Partners in Care include:

Schizophrenia – a booklet providing an overview of this illness, its symptoms, suggested causes, different treatments, and how to help

Severe mental illness (psychosis) – aimed at carers of people with this illness and members of the mental health team, this pamphlet suggests ways of improving communication and liaison to allow mutual respect and real working partnerships to develop from the point of diagnosis.

You can order these booklets along with a catalogue of other materials by contacting the Leaflets Department, Royal College of Psychiatrists, 17 Belgrave Square, London, SW1X 8PG or E-mail: leaflets@rcpsych.ac.uk. Further information about Partners in Care can be downloaded from www.partnersincare.ac.uk

Toolkit for Supported Employment

The U.S. Department of Health and Human Services has published a Supported Employment program toolkit. It is available at their National Mental Health Information Center:

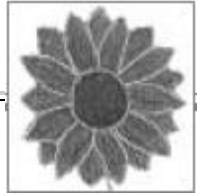
www.mentalhealth.samhsa.gov/cmhs/communitysupport/toolkits/employment

Supported Employment is a well-defined approach to helping people with mental illnesses find and keep competitive employment within their communities. Programs are staffed by employment specialists who have frequent meetings with treatment providers to integrate supported employment with mental health services. The core principles of this program include:

- Eligibility based on consumer choices and preferences
- Supported employment as an integrated treatment
- Continuous follow-along supports
- Help with moving beyond the patient role and developing new employment-related roles as part of the recovery process

The toolkit provides an introduction to Supported Employment as well as a chapter on each of the following:

- Research showing that Supported Employment works
- The core set of principles that form the foundation of Supported Employment
- Who can benefit
- Strategies for engaging consumers in Supported Employment
- Assessing a consumer's interest and work experience
- Issues involved in a job search
- Job supports that facilitate successful competitive employment
- Interpersonal skills that will support consumers
- Harnessing help



Consumers Enjoy the Healing Power of Gardening



These men are patients working in the garden adjacent to the psychiatric hospital at Paramaribo in Suriname, South America. For years this part of the garden was just weeds, but with the help and support of their doctor and social worker the patients and their family members have had great success. The patients have also built their own shaded garden house to keep orchids and other flowers. Photo courtesy of Joyce Dawson, Chairman of the family organization Ypsilon, Suriname.

New WHO Resource Book Addresses Inequalities for People with Mental Disorders

Global experts and stakeholders in mental health, law and human rights have collaborated in a landmark publication from the World Health Organization (WHO). The **WHO Resource Book on Mental Health, Human Rights and Legislation** gives countries an important new legal tool to help address the often unacceptable conditions in which people with mental disabilities live. The book is intended to guide countries and support stakeholders in creating mental health legislation. Hundreds of experts/stakeholders throughout the world provided input. WFSAD President Dale L. Johnson and John Gray, a legal expert on our Board, were among those who reviewed the documents. Copies of the book can be downloaded at www.who.int/mediacentre/news/notes/2005/np14/en/index.html

UK Advocate Calls for Better Discharge Planning and Follow-Up for Psychiatric Patients

Marjorie Wallace, Chief Executive Officer of SANE UK, has called for reform of the way in which psychiatric patients are treated.

“SANE believes that many of the 40 homicides a year committed by people in contact with mental health services, if not predictable, could have been prevented had the patients been properly treated and cared for and not allowed to discharge themselves, abscond or simply leave psychiatric wards, with little effort being made to follow them up or give adequate information to families, police or those entrusted with their care.

“There seems to be a worrying increase in the numbers of patients who are allowed to disappear in the community while they are extremely disturbed, who then commit suicide and occasionally attack others. These cases further shatter the public’s confidence in the care provided for in the community policy and increase the stigma for the majority of people with mental illness who are never violent.”

SANE is one of the UK’s leading charities concerned with improving the lives of everyone affected by mental illness. The organization has three objectives:

- 1) to raise awareness and respect for people with mental illness and their families, improve education and training, and secure better services
- 2) to undertake research into the causes of serious mental illness through The Prince of Wales International Centre for SANE Research
- 3) to provide information and emotional support to those experiencing mental health problems, their families and carers through SANELINE.

You can learn more about SANE at

www.sane.org.uk



Sally's Story

How does it feel to develop a mental illness like bipolar disorder when you're still a teenager at school? Sally tells about her experience, about how she reacted, and the things that helped her get her life together again.

I sat in a corner at school, feeling scared of everything and crying my eyes out. People asked me "What's wrong?" but I could not answer. I was in year 12. It was my first full-on episode of depression.

Pretty soon, even leaving home seemed an overwhelming idea, so I just stayed in for months on end. I stopped meeting people. I hardly ate – my weight dropped to 42 kg.

Looking back, there had been signs since I was 13 or even younger that I was having mood swings ... sometimes my mind would be going a million miles an hour! But I just thought that was me, that it was my personality.

Even though the symptoms were so awful, you still think that how you feel is just "how things are," that that's the way the world is. It's really hard to recognize and accept that how you feel inside is actually caused by an illness, and I ran from treatment for years.

Something else that really hurt at the time was how some of my friends stopped seeing me. I guess I was too much hard work for them, and they couldn't be bothered. Others were confused and scared because they knew nothing about mental illness. The good thing is that those friends who've really stuck by me are real friends.

I was in my late teens when I began to accept that I did have an illness and did need treatment to get better ...

When I was 18 I had a really bad episode of depression. Everything seemed pointless. I could barely speak. That's when I was admitted to hospital.

Things were so serious, they gave me a course of ECT (electro convulsive therapy) as well as my medication. The thought of it

scared me at first, but I believe to this day the ECT saved my life. It really did break the depression and helped me to begin to feel normal again.

I was diagnosed with bipolar disorder, and once I accepted this, I could accept I needed treatment for it ... and that made everything easier. I could start to confront things and think "OK, so what am I going to do about this?"

Now that I've got a good relationship with a doctor and symptoms are mostly under control with the medication, things are pretty good. It's been a relief in a way just to accept that I have an illness that needs treatment, in the same way that someone with epilepsy or diabetes would. Understanding what's happened to you makes all the difference ...

Having people around, family and friends, who understand and support you is so important. The more people you feel comfortable telling, the more accepted and "normal" it feels to have a mental illness. A trusting relationship with a doctor who knows you, and you get on with, is important too. That goes for your GP as well as your psychiatrist. I've been lucky like that, I guess. Some people's doctors change much too often and they don't get a chance to build up any sort of relationship.

Another thing that really helps is learning as much as you can about the condition affecting you, about treatment, about what you can do to help yourself. That's why information like the books and other resources SANE produces is so valuable. The more you understand, the more normal it seems. You feel you have more of a handle on what's happened to you, and it's easier to talk to others about it.

And you know, it's amazing how many people would then say, "Guess what ...?" and tell me about mental health problems they've had. It just shows that when people are open about mental illness, it makes life easier for everyone.

(Source: SANE News, issue 33, Autumn 2005; www.sane.org)

The Bit Where You Lay Awake ALL Night

... the bit where you lay awake ALL night 'cause your mind's racing a mile a minute and you can't keep a train of thought for more than a minute or two and you get those bloody "psychomotor agitation" symptoms and you have an irresistible urge to babble about anything and everything and you start talking really fast so you can get it all out and you start copying

all five pages of Act III, scene ii, lines 1-190 of *Merchant of Venice* just 'cause you kind of like that scene and for some reason you have a virtually uncontrollable urge to start singing every little piece of tune that comes into your head, even when it's something you HATE or isn't actually a song and you even type in run-on sentences ... *(Source: www.bipolaraware.co.uk)*



(Continued from page 3)

teers, involved supportive psychiatric and psychosocial professionals and financial support (but it is surprising how much can be achieved with the first two alone).

While most organizations do not offer courses focusing on particular stages of caring, formal education is the way that many family self-help and advocacy associations have gone. Many years ago the WFSAD newsletter focused on the New Zealand Schizophrenia Fellowship that led the way by offering a course for families and carers given at Palmerston College in North Island, New Zealand. The course was modelled after a course given at the Boston College Graduate School of Social Work. Later we reported on the Rethink Sainsbury Centre course offered in England. More recently we focused on the NAMI Education, Training and Peer Support Centre (WFSAD Newsletter 3rd Qtr 2003, P.6-7) that has broadened its focus and now includes courses for families, consumers and providers. The latter are those working in the mental health system, for example in mental health housing, who often have no previous training about mental illness. Then in 2004 "Strengthening Families Together" was launched by the Schizophrenia Society of Canada. This offers a 10-session educational course for Canadian families.

The most recent program of a similar nature has been developed by the European Federation of Associations of Families of People with Mental Illness – EUFAMI – which has three courses under the name "Prospect." More information about Prospect appears on page 14. All these programs have been developed with generous foundation and pharmaceutical industry support.

Anil Vartak of Pune, India, has also developed an approach, which we are pleased to review briefly on page 7 of this issue.

Reaching More Families

Despite the encouraging development of formal educational courses for carers, consumers and providers, given by self-help organizations, not all families can be reached. Reasons for this are often cultural, again because some view mental illnesses as shameful or fateful or mysterious, or simply because of the fear surrounding the mere words used for these illnesses. At a recent workshop titled "The Carer's Journey" held in Buckinghamshire, England, Professor Julian Leff spoke of some of the traditional concepts of mental illness in the developing world. Causes were ascribed to "angered an-

cestral spirits; black magic or evil eye and fate.' In many places, family support needs to reach people with this mind-set. It must seek innovative ways to spread the word: medical and social knowledge are allowing us to give aid, treatment and support that will reduce the symptoms and disabilities associated with these disorders. People need to know this. We need also to understand the societal and family hierarchies in our own and other cultures in order to address problems in an appropriate way. Broadcasting one's own services and successes can be done at local business fairs, disability fairs, social occasions like seasonal community fairs and in local newspapers and radio stations. Open houses should be the province of all support organizations and indeed of mental health clinics which need to be de-mystified.

Professional Care and Services

Psychiatric professionals involved with the care of persons with mental illness must include both the family and patient (consumer) in discussions of pharmacological and psychosocial treatment to get the best functional outcomes even when symptoms remain.

In its strategy "Families as Partners in Care" WFSAD continues to promote comprehensive, integrated long-term care that includes families/carers. A copy of the booklet *Principles for Working with Families* developed by the WFSAD Strategy group, can be obtained from the WFSAD office. Feeling that they are a valued member of the treatment team is a wonderful experience for a family. So often families are very tentative about raising important issues that they face in the day-to-day experiences with their family member who is unwell. Having immediate contact with families can also be a significant adjunct to treatment for clinicians. In this way everyone feels connected and the exchange of information can improve a person's treatment.

Diane Froggatt would like to acknowledge Joyce Burland, Celia Soden, Anil Vartak, Bridget Hough and Judy Sinyard whose personal communication or writings assisted in the preparation of this article.

Tell Us Your Family Support Stories

Family organizations comprise a lot more than the support that is key to their existence, but those accomplishments are for another article. Let us know how, in the broadest sense, you are supporting families and we will publish your news. Contact us at:

www.world-schizophrenia.org

Taking Steps Towards a Successful Career in the Food Service Industry

Just like many other groups of people, people recovering from addiction and mental health issues have a vast array of skills and experience to contribute to the labour force. However, many are unemployed or underemployed and struggle with poverty and low self-esteem in addition to their illness. Aware of this challenge, a joint effort was created by George Brown Toronto City College and the

Centre for Addiction and Mental Health (CAMH) in Toronto, Canada. This partnership launched *Assistant Cook Extended Training (ACET)*, which helps people recovering from addiction and mental health take the first step towards a job in Toronto's food service industry.



The Forgotten Generation

The UK charity Rethink severe mental illness launched the second stage of its Forgotten Generation campaign in April 2005. The campaign aims to help end the tragedy of the Forgotten Generation of 50,000 people with severe mental illness whose mental, physical and social needs are ignored. These are people with severe mental illness living in the community who have been largely forgotten by mainstream mental health services. For the most part, these are the people who have lived with a severe mental illness for many years, passing through and surviving a series of early crises, feeling rejected by society and who now live their lives without the all-round help and support that would allow them to raise their quality of life.

The campaign was launched following the huge response to an article by Pauline Arksey in Rethink's members' magazine *Your Voice*. She wrote about her concerns about who would care for her son when she was no longer able to.

The report *Action Stations* and toolkit *Make a Fresh Start* were launched in April 2005, and offer health professionals, family members and mental health service users practical solutions to improve the quality of life of the Forgotten Generation.

The report *Action Stations* found that:

- The services the Forgotten Generation rely on are often being closed to fund other services
- The Forgotten Generation are shunned by services because of strict referral criteria
- GP practices need to offer more services to people in the Forgotten Generation, including physical health checks.

The launch of *Action Stations* and *Make a Fresh Start* took place at the Cabinet War Rooms in central London. In keeping with

the venue, a theme of "rationing" was chosen – the message was that the resources of the mental health system were not being shared fairly and that the Forgotten Generation, in particular, are not currently getting their fair share of the rations.

In addition to the report and action pack, attendees were given a mock-up "fair ration book for the Forgotten Generation." This included coupons for yearly physical health checks and medications reviews, fortnightly flexible benefits, daily contact with community services, daily meaningful occupation and sessions on psychological therapies, exercise, prescription and self-management groups.

A wide range of guests attended, including media representatives, professional representatives, representatives from the UK's Number 10 Strategy Unit and Disability Rights Commission.

The theme of rationing was carried through the event – as guests arrived, they were split into two groups, one of which was provided with coffee, tea, etc. – the other was only able to access a more basic refreshments table of orange squash and "economy" biscuits. Gerry McCarthy spoke about his experiences as a service user, including an episode where he almost lost CPN contact. Pauline Arksey spoke from a carer's point of view and stressed that the Forgotten Generation were a "timebomb."

The event received considerable media coverage of the launch, including the BBC Online, two national newspaper websites and the British Medical Journal.

For more information contact Rethink Front Door on +44 845 456 0455 or go to: www.rethink.org, click on News & Campaigns and then Forgotten Generation.

News from Goa

"Who says there is no hope?" was the theme of a one-day seminar held recently in Goa, India, that attracted over 100 carers. Topics included the function and structure of the brain (Dr. Peter Castelino); modern treatments (Dr. Ajoy Eteiberiro); psychological treatment (Dr. Melvin Chagas Silva) and rehabilitation (Janet Dias). Namdev Gawas spoke on "Carers Joining Hands." A

skit on Mental Health Myths and Realities plus songs by a consumer choral group were well received.

Gawas also presented a research paper at Shree Damodar College of Commerce and Economics, Marga, Goa early in February 2005. Written by Gawas and Satish N. Sawal it was entitled Sadness in Paradise: Mental Health in Goa.

Introducing APAMM - A Mental Illness Support Organization in Algiers

APAMM -- the Association of Families and Friends of the Mentally Ill -- is an organization in Algiers, Algeria. At present they have two locations of which one -- on the west side of Algiers -- is fully functional. It has personnel who organize several activities with the goal of reinsertion into society, as well as support and help for families, through all medical treatment and enforcement of human rights of the mentally ill. There are many women among the doctors, lawyers, psychologists, social workers, etc. who are involved. They are motivated by a great desire to open, for the first time in Greater Algiers, the maximum number of centres, and then to reproduce them across Algeria.

According to the association, there are 1.6 million individuals in Algeria who suffer mental disorders. APAMM is supported

through State subsidies, membership fees, legacies, donations and through the sale of its publications.

The organization is based in a large suite of seven rooms where one can find informative materials, a workshop for painting on silk, a patisserie workshop, and a workshop for manual work. The patients are free to do what they want with help from a supervisor. Therapy groups are being formed. They are hoping to soon have a line to the internet.

Thanks to Louisa Samar for sending us this information.

To contact this association write (in French) to: APAMM, Centre de Socialisation Djamel Eddine BENFERHAT, 100, Rue Didouche Mourad, Alger (Algiers), Algeria.

Tél/Fax: 00 213 21 74 29 40

Wish List Kadilkoy, Istanbul

Aysel Dogan, Director of Schizophrenia Association Kadilkoy in Istanbul, Turkey writes that the association has many activities including an art program, a Folk-Dance Show that has travelled to Germany, Holland and Sweden (see photo in a previous WFSAD Newsletter). The schizophrenia patients who four-to-five years ago could not go alone outside of their houses and didn't speak to anyone, came every day on their own and even travel abroad with the dance troupe. "We are very proud of the success of this program," Aysel writes. "But we would like to have a clubhouse because people need to work and earn some money. Their families don't have the ability to support them and there is no financial support from government." If you can help the patients of Kadilkoy Istanbul, please contact Aysel at bahadyr@yahoo.de and support their dreams of a clubhouse.

Nairobi, Kenya

The Schizophrenia Foundation of Kenya is seeking funds to purchase medications for its members. It has had a project to purchase medications since 2002, but funds are almost finished. Anyone interested in donating to this cause should contact Patricia at WFSAD by writing to our Toronto address or sending an email (see page 2).

AASHA Opens 2nd Shop

AASHA, Chennai, India, formally inaugurated its second shop on June 11, 2005. Four mentally-challenged people are employed in the shop. A photocopying service and a pay-telephone have been installed. Along with other merchandise the shop sells AASHA-Brite Cleaning Powder, which incidentally is packed in the Occupational Therapy Centre at AASHA Halfway Home.

In the past two years, AASHA has been able to place 11 mentally-challenged people not only in our Retail Selling Outlets but also in private industrial organizations within city limits. The only service provided by AASHA is a volunteer transportation service from their residence to respective places of employment. In addition, one AASHA resident has been completely reintegrated into mainstream society and is now living with his own family. We look to achieving small successes to derive motivation.

Report from Ratna Chibber

Note: We are sure that AASHA would like to hear from you. Exchanges of information and greetings are much prized by all our small members. You may contact AASHA: Ratna Chibber, President, AASHA, Old 35, New 56, Bunder Garden, Main Street, Perambur, Chennai 600 011, India or by email: ratna@md3.vsnl.net.in



The Family Bill of Rights and Not-So-Rights

The Family Bill of Rights

Families giving support and care have the right:

To speak

To ask questions

To be present

To be treated with respect

To know (about the illness – education)

To be informed

To have a logical and reasonable treatment plan

To have a 2nd opinion without prejudice or discharge.

“Cannots” or “Can’ts” for the Family

The family cannot be the agent of cure.

The family cannot get their actions right all the time.

The family cannot have power over the illness.

The family cannot be entirely objective (in the face of insult etc.)

But

The family cannot give up.

Both the above from Dr. Anthony Levitt at the recent “Family Matters” conference in Niagara Falls., Ontario, Canada.



Prospect Educational Courses

Prospect education programs are the result of three years of study by the

their quality of life by social and work integration.

European Federation of Associations of Families of People with Mental Illness (EUFAMI) in consultation with experts in education and empowerment. Fourteen EUFAMI members are involved. Four programs include the best practices of all the involved countries. The philosophy behind the programs is to break the cycle of isolation and to develop skills to enable people to live with mental illness and to regain their quality of life. The programs are as follows:

People with Mental Illness:

To work towards social integration that will allow people with mental illness to improve

Mental Health Professionals

To analyse the barriers in communication and ways to overcome these; viewing the professional as a capacity builder and facilitator in care management for the unwell person and his/her family; discussion of the difficulties and plans of action.

Families and Friends

Improving self confidence; to allow those close to the unwell person to explore internal and external means by which they can improve their quality of life.

Each course is given by trained personnel

The Rap

By Celia Soden

“Walking on eggshells”, “driving through fog”
Are some of the phrases in our catalogue
Of comments from carers whose unbidden fate
Bears the difficult task to communicate

So, this is how you communicate –
You write a letter and then you wait
And you wait and you wait
Oh Lord how you wait –
Now that’s no way to communicate!

This is how you communicate –
You make a call and then you wait
And you wait and you wait
Hearing music you hate –
Now that’s no way to communicate!

This is how you communicate –
You leave a message and then you wait
And wait and you wait
Til its often too late –
As I said, no way to communicate!

If you get someone who’ll communicate
It’s a fairly sure bet they’ll abbreviate –
CPA, CPN, SBMHT –
PALS, CESP, PPI – all Greek to you and me!

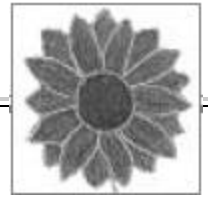
Now here’s a great way to communicate –
This Carers’ Conference – the third to date
You can ask your questions,
Find others who relate
To the worries you are facing
And the problems on your plate.

There are agencies to help you,
Loads of bumb to illustrate
Where you can find some answers –
So let’s communicate!!

who belong to the group they are training in order to give the education real meaning and authenticity.

The Common Ground Module

Brings members of all three target groups together to discuss and brainstorm over productive communication. For more information about EUFAMI and Prospect contact EUFAMI at one of the following: EUFAMI, Diestsevest 100, B-3000 Leuven, Belgium; or www.eufami.org/prospect/en/



WFSAD News—Kudos for WFSAD Personnel



Diane Froggatt, Secretary and Development Officer of WFSAD was recently presented with the Warren Williams Award of the American Psychiatric Association, North Eastern Section, for 21 years of unstinting work to improve the lives of families and persons suffering mental illness. She was happy to receive her award from Dr. David Freebury, a psychiatrist she has had the pleasure of working with for many years.



Jim Crowe, WFSAD Past President, receives the prestigious College Citation from Dr. Phil Boyce, Past President of the Royal Australian and New Zealand College of Psychiatrists, May 10, 2004, in Christchurch, New Zealand. The report of Jim's award appeared in the Third Quarter 2004 Newsletter.

News from Our Asian Secretary, Jim Crowe

I recently accepted an invitation for a three-week visit to India as the guest of Dr. P.D. Boaz. I will speak at the 40th Anniversary Celebration of the Dr. G.D. Boaz Memorial Hospital School, a Psychiatric Rehabilitation Centre that was founded by his father.

Dr. Boaz senior had been trained by Mrs. Sarada Menon, the leading light of the Schizophrenia Research Foundation India (SCARF). Mrs. Menon will also be taking part in the celebration.

The Centre, which I visited when I was last in India during the WFSAD World Conference, is quite extensive and caters both for those who can afford to be there and those who cannot.

I am very pleased to be able to represent WFSAD at this

event. It is so important to get to know people who work at the grassroots. It enables us to reach those families we might never meet. Once more I look forward to meeting families in their own homes.

I intend also to visit Dr. Thara at SCARF and to spend time with AASHA which is planning to open a second shop during his visit. The washing powder which the people make is selling well. The first shop is still going strong and making a good profit.

Recently I was surprised and delighted to be invited by Dr. Julian Freidin, President of Royal Australian and New Zealand Psychiatric Association (RANZCP), to be an inaugural member of the President's International Advisory Committee at RANZCP.



EVENTS

XII World Congress of Psychiatry: 5000 Years of Science and Care

September 10-15, 2005

Cairo International Convention & Exhibition Center, Egypt

Further information can be found at:

www.wpa-cairo2005.com

WPA Regional Meeting

October 30-November 2, 2005

Los Cabos, Mexico. Further information from:

Dr. Luis E. Revero Almanzor

aspsiqm@prodigy.net.mx

WFSAD World Conference Mental Illness Today: Hope in Action Toronto Canada, October, 2007

We are delighted to announce that our hosts for our 25th anniversary world conference will be the Schizophrenia Society of Canada and the Schizophrenia Society of Ontario. The conference will be held in Toronto in late September or early October.

Planning meetings have already begun and we plan to send our first flyer out to members as soon as the exact date is confirmed.

**Mark your calendar
and plan to be there.**

