

Patient Education Plan Guidebook



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The TMAP Patient/Advocacy Committee would like to thank Mary Dees, Carolyn Canfield, and Jim Lochhead for contributing their ideas and artistry to the creation of the patient education materials. Also thanks to Gus Sicard for the tremendous effort involved in translating all the materials into Spanish.

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❖ *Overview of TMAP*

For patients with severe and persistent mental illnesses (SPMI), medication treatment guidelines, or algorithms, may bring uniformity of treatment, predictability of costs, and quality of care at overall lower health care and social costs. Treatment guidelines may also provide a benchmark against which to monitor care and to evaluate treatment programs.

The potential of these benefits has never been formally evaluated in SPMI patients. In fact, only recently have medication treatment guidelines been sufficiently developed, and accepted consensually, to allow evaluation of their benefits and costs. In addition, studies of medication efficacy have seldom aimed at comparing the benefits of several medication options given either initially, or given sequentially in treatment in the face of partial response or failure to respond. Studies defining paths through the medication maze that are most helpful for particular patient subgroups can add to our knowledge and improve treatment plans.

The Texas Medication Algorithm Project (TMAP) is designed to determine the clinical and economic value of the use of prespecified medication algorithms (ALGO) in combination with clinical support and a prespecified patient/family educational package (ED) in the pharmacologic management of patients with one of three major mental disorders: schizophrenia (SCZ), bipolar disorder (BPD), and major depressive disorder (MDD), each compared with treatment-as-usual (TAU) in the public mental health sector. TMAP has evolved into a unique and productive public-academic partnership among the Department of Psychiatry at UT Southwestern Medical Center, the Texas Department of Mental Health and Mental Retardation (TDMHMR), the UT College of Pharmacy, the Texas Department of Criminal Justice, and the departments of psychiatry at four other Texas medical schools. Its major goal is to improve the quality of treatment to public sector patients while, hopefully, containing the cost of services over a patient's lifetime involvement with the service system.

Background: In late 1995, TDMHMR decided to develop and implement pharmacotherapeutic algorithms for treatment of the three major disorders most commonly treated in the Texas public mental health system: schizophrenia (SCZ), bipolar disorder (BPD), and major depressive disorder (MDD). This decision was greatly influenced by observations that significant variance existed in the manner in which these conditions were treated by physicians across the state. Additionally, changes in health care financing had dictated that methods be implemented to contain health care costs while retaining or improving the quality of care.

Managed care organizations in both the private and public mental health sectors are adopting, and in some cases mandating, the use of guidelines and algorithms in patient care. Since inadequate data currently exist to support the

hypothesis that pharmacotherapeutic algorithms improve the outcomes of patients with severe mental disorders, TDMHMR initiated an evaluation of the use of algorithms in treating patients in the Texas public mental health system (Phases 1 and 2 of TMAP).

TMAP is unique in several ways. The algorithms were developed for specific use in the public mental health sector. From the onset, their development included the input from providers in the public sector and from patients and families receiving treatment. An important benefit of this latter participation has been the development and adoption of educational materials that provide information to patients and families on the specific disorder causing their symptoms, on the medication sequence recommended by the algorithms, medication side effects, and methods that patients and families can use to manage symptoms and side effects.

Phase 1: The first algorithm developed, major depressive disorder, relied on the formal consensus conference method. A consensus panel convened that included national experts, Texas public mental health sector practitioners who were to implement the algorithm, patients, family members, and Phase 2 pilot site administrators.

Schizophrenia and bipolar algorithms were developed based upon the expert consensus guidelines from the Tri-University Project (Frances et al., 1996; Kahn et al., 1996). These guidelines relied on a modified RAND Corporation method where a questionnaire with a 9-point scale was used to elicit consensus from a large panel of experts on a variety of clinical questions.

TMAP held two conferences – one for bipolar and one for schizophrenic disorders – at which the Tri-University guideline authors presented their draft guidelines to an audience of TMAP participants including other academic experts, TDMHMR practitioners who had volunteered to implement one of these two algorithms, families, and patients. At the end of these conferences, the TMAP module co-directors for these two algorithms elicited feedback on the guidelines from the practitioners who were to implement the algorithms. This feedback led to modification of the Tri-University guidelines and translating them into algorithmic form. These bipolar and schizophrenia algorithms were then implemented in TMAP Phase 2.

Each algorithm is multi-staged. Each stage describes a treatment strategy. There are two algorithms for major depressive disorder — one for psychotic and one for nonpsychotic depression. The former has four stages or steps, while the latter has seven. The schizophrenia algorithm has four treatment stages, as well as a side effect algorithm and an algorithm for managing co-existing symptoms with adjunctive medications. For bipolar disorder, there is a seven-stage algorithm for the manic phase and a six-stage algorithm for the depressed phase.

Each algorithm includes the particular medication(s) or medication class(es)

recommended at each stage (i.e., the strategies), as well as the relevant tactics (i.e., the preferred oral doses or serum concentration ranges, the time to remain at the dose, common side effects, and how to evaluate them). In the tactics, each algorithm focuses on key decision points regarding whether to continue the medication unchanged, modify the dose, discontinue the medication and begin a new medication, or augment the first medication with a second medication. The algorithm tactics also recommend the frequency of visits required for proper evaluation.

The algorithms identify treatment strategies at each stage that are relatively equivalent in their expected efficacy and medical safety as determined by the scientific literature and/or expert clinical judgment. The earlier treatment stages in each algorithm tend to be simpler in implementation while the later stages more complicated and more demanding of patient adherence. The earlier stages tend to have fewer potential significant side effects than the later stages which tend to have higher medical risk. The early stages are also based more upon scientific evidence while the later stages depend more on expert consensus. When multiple strategies at a given stage are equivalent (i.e., one alternative seems as valuable as another), these strategies are presented to clinicians and patients as options. The patient/family educational materials, by providing knowledge about symptoms and side effects, help patients collaborate with their physicians in making informed choices with respect to treatment options defined in the algorithms. It is hoped that such efforts will increase patients' adherence with the selected treatments.

Phase 2: Fifteen separate sites (7 inpatient and 8 outpatient) and 36 physicians participated in Phase 2. While the general rule was for each site to enroll patients in only one algorithm, three sites enrolled patients in multiple algorithms. At each site, for each algorithm, there were two participating physicians whose goal was to enroll 10 patients into the algorithm they had been assigned. Physicians were encouraged to enroll any patient for whom they were rather certain of the primary diagnosis for which the algorithm was intended, and for whom they judged a change in the medication (not simply dose) was indicated to treat the primary syndrome (i.e., schizophrenia, bipolar, or major depressive disorder). Thus, patients beginning medication treatment and those already taking a medication that was not producing a satisfactory effect were eligible.

The methodology for Phase 2 was consistent with the primary objective of determining the feasibility of implementation. Patients entered the algorithm over a six-month open enrollment period, and were followed for up to four months of treatment with the algorithm.

Data collection instruments and procedures were developed and refined, as were project management and physician training processes.

Phase 2 enrollment closed April 7, 1997, with 235 enrolled. These patients were followed through August 7, 1997, after which final data analyses and publications

were completed. Final adjustments in this Phase 3 protocol based on Phase 2 data analyses were completed by December 1, 1997.

Phase 3: Phase 3 will evaluate the clinical and economic impact of medication treatment algorithms for the three most common disorders treated in the public mental health sector: SCZ, BPD, and MDD, each compared with TAU in representative clinics of the TDMHMR care system in 7 geographical sites across the state of Texas. (See Table 1 for a table showing all TMAP clinic sites and the different groups of study patients in each.) Subject entry will occur over a 9-month period, with follow-up of each patient occurring for at least one year after entry into either ALGO + ED or TAU cells. Research outcome evaluations will occur at baseline and every 3 months thereafter for all ALGO and TAU patient groups. These assessments will collect measures of symptoms, level of functioning, clinician and patient satisfaction, mental health and medical service utilization, and interim contacts with the civil or criminal justice systems and the welfare systems.

Patients must be at least 18 years old. Patients eligible to enter ALGO or TAU are those with the requisite clinical diagnosis (SCZ, BPD, or MDD) for whom their physicians and they decide that medication initiation or a change in medication (not simply dosage adjustment) is clinically indicated. We anticipate the enrollment of approximately 1,755 subjects into the study. Patients eligible to enter ALGO or TAU will have the study described to them by their physician or another clinical staff member. Patients who provide written informed consent will be enrolled in the study.

Data Collection: Clinical data will be gathered every 1-4 weeks for all patients enrolled in an algorithm (ALGO). A Medical Record Review will provide additional data by extracting information from the clinical record that will provide a gauge to the degree to which the physicians followed or approximated the recommendations in the ALGO. The Structured Clinical Interview for DSM-IV-Clinician Version will be conducted with patients who fail to respond to treatment to assess the accuracy of their diagnoses. Research outcome data will be gathered quarterly from all patients (ALGO and TAU). Utilization and cost data will also be gathered every 3 months on all subjects. All data will be sent to Dallas for data entry.

The activities and methods developed in each of the three phases of TMAP are illustrated in Table 2.

References

Frances A, Docherty JP, Kahn DA: The expert consensus guideline series, treatment of schizophrenia. *J Clin Psychiatry* 1996; 57 (suppl. 12B): 1-58.

Frances A, Docherty JP, Kahn DA: The expert consensus guideline series, treatment of bipolar disorder. *J Clin Psychiatry* 1996; 57 (suppl. 12A): 1-88.

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Introduction to Patient Education Plan

Patient education and involvement with treatment are essential to achieving successful patient outcomes. Therefore, while developing medication algorithms, we realized a need to also develop a program which would educate patients and their families about their illness, and empower them to become involved with treatment planning and management. Specifically, we expect that a well-designed and well-delivered patient education program will lead to:

- 1) improved relationships (therapeutic alliances) among the patients, families, physicians and other clinicians;
- 2) more active and full participation of patients and families in treatment, including better self-management of symptoms and side effects;
- 3) improved adherence to the prescribed treatment regimen;
- 4) improved patient/family skills in chronic disease management.

We also expect physicians to make better clinical decisions because they will have improved communication with the patients about their illness status and treatment needs. Ultimately, we expect the above effects to contribute to improved treatment outcomes.

The patient education plan has been co-developed with patients and patient advocates to ensure that patients' needs and expectations are addressed. Some of the collaborators in this endeavor are the Texas Alliance for the Mentally Ill, the Mental Health Association in Texas, the Depressive and Manic-Depressive Association, Texas Mental Health Consumers, and the TDMHMR Office of Consumer Affairs. In addition to patient education, our collaborators have been involved in the development of the medication guidelines and dissemination of information about TMAP to other patients/families, and they will continue to participate in evaluation of the results of TMAP, including the Patient Education Plan.

Several educational needs are addressed by the plan. The materials and plan provide:

- X information about the illness and treatment alternatives,
- X information about specific medication effects and side effects, and
- X ideas for how patients can recognize and manage symptoms and communicate their illness status and treatment needs to clinicians.

We have attempted to develop an education plan that (1) provides phased information, i.e., from simple to more complex; (2) can be targeted to individual needs; (3) reinforces through repetition of key information; (4) makes use of

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multiple learning modalities (e.g., visual, aural and experiential); (5) incorporates both individual and group formats; and (6) involves consumer/family participation as educators.

The education plan utilizes materials that are specific for three disorders: major depressive disorder, bipolar disorder, and schizophrenia. The purpose of these materials is to address the concerns, needs, and expectations of patients with a particular illness. The following pages describe these materials in more detail and provide guidance for utilization of the materials with patients and families.

Patient Education Materials

① Information about Illness

- Disorder Fact Sheets

These are glossy one-page documents that provide general information, with visual depictions of the brain and symptoms of the illness. The key messages of these documents are that the illness involves brain functioning, that the disorder has specific symptoms associated with it, and that patients do get better with treatment.

② Medication Information

- MedCoach Medication Fact Sheets

These are one-page copies of specific medication information from the U.S. Pharmacopoeia. These sheets are intended to educate the patient on proper use of the medication and possible side effects.

- Medication Benefit Sheets

These sheets describe the positive effects of four classes of psychoactive medication and should be provided along with the MedCoach sheets.

③ Symptom and Side Effect Monitoring and Coping Materials

The intended purposes of these materials are to aid the patient with monitoring, managing, and coping techniques.

- Symptom and Side Effect Sheets

These are one-page documents that ask the patient to rate the severity of symptoms and side effects. On the flip-side of the document are visual depictions of symptoms that may help the patient recognize which symptoms have been present. The intended use of these sheets is to help the patient monitor the disorder.

- Suggested Techniques for Coping with Persistent Symptoms

This document provides suggestions on how to cope with persistent symptoms of the illness.

- Side Effects Check List Sheet 1: Less Severe Symptoms

This document provides suggested actions to take for various side effects from medication

- Side Effects Check List Sheet 2: More Severe Symptoms

This document provides a list of potential side effects of medication that are more severe. If the patient experiences any of these side effects, he or she should contact the doctor right away.

④ **Basic Disorder and Treatment Information**

These documents provide information about the disorder and general information about medication.

- *Understanding Schizophrenia: A Guide for People with Schizophrenia and Their Families* (glossy booklet)
- *Expert Consensus Treatment Guidelines for Bipolar Disorder: A Guide for Patients and Families* (article)
- *Conquering Depression* (glossy booklet)

⑤ **More In-Depth Materials**

These documents provide additional information about the disorder and treatment.

- *Expert Consensus Treatment Guidelines for Schizophrenia: A Guide for Patients and Families* (article)
- *Living with Manic Depressive Illness* (larger glossy guidebook)
- *Treating Major Depression: A Patient's Guide* (glossy booklet)

⑥ **Videotapes and Discussion Materials**

These materials provide audiovisual information about the disorder and treatment. They are intended for group or individual use. Each video is accompanied by guidelines to facilitate group discussion following tape viewing.

- *Living with Schizophrenia*
- *Dark Glasses and Kaleidoscopes: Living with Manic Depression*
- *What's with You, My Friend? Images of Depression*

⑦ **Consumer-To-Consumer Group Discussion Materials**

These materials are visual depictions (in the form of overhead slides) of various discussion-provoking messages, such as symptoms, medication usage, side effects of medication, and myths and fallacies about mental illnesses. The intended use of these materials is to encourage group discussion of issues that pertain to patients' situations, to dispel myths, and to facilitate discussion with others who have similar perceptions, problems, or situations.

- ⑧ **Support Group Information**
Names, addresses, and phone numbers of local support groups for patients and families.

References

Conquering Depression. NARSAD Research

Dark Glasses and Kaleidoscopes (Video). National Depressive and Manic Depressive Association (NDMDA)

Expert Consensus Treatment Guidelines For Bipolar Disorders: A Guide For Patients And Families. Kahn DA, Ross MA, Rush AJ et al. J Clin Psychiatry 1996;57 (Suppl 12A): 81-88.

Expert Consensus Treatment Guidelines For Schizophrenia: A Guide For Patients And Families. J Clin Psychiatry 1996; 57 (Suppl 12B): 51-58.

Living With Manic-Depressive Illness: A Guidebook For Patients, Families, and Friends. National Depressive and Manic Depressive Association (NDMDA), Revised 2/98

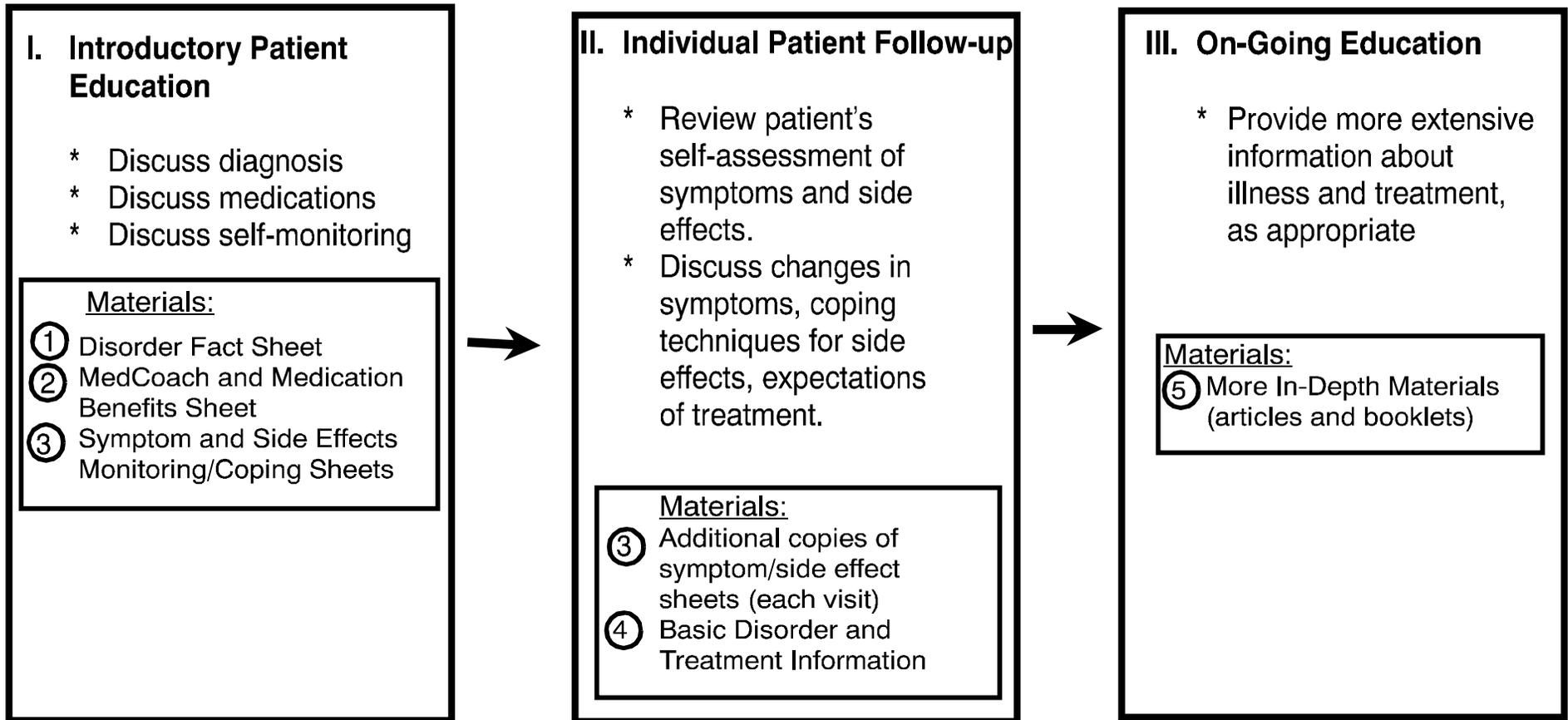
Living With Schizophrenia (Video). National Alliance for the Mentally Ill (NAMI)

Treating Major Depression: A Patient's Guide. New York State Psychiatric Association.

Understanding Schizophrenia: A Guide For People With Schizophrenia And Their Families. NARSAD Research

What's With You, My Friend? Images of Depression (Video). The Mental Health Association of Minnesota (Distributed by Media Inc.)

Patient Education Plan Diagram



At Appropriate Time:

<p>IV. Group Education</p> <ul style="list-style-type: none"> * Provide opportunities for patients to learn from/support each other. * Provide referrals to support groups. 	<p><u>Materials</u></p> <ul style="list-style-type: none"> ⑥ Videos and Discussion Materials ⑦ Consumer-to-Consumer Discussion Materials ⑧ Support Group List
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Patient Education Plan

We have developed a plan with a “phased” structure in mind. It is intended that simple, easy-to-understand information be provided to the patient during initial visits, and as appropriate, more complex information be provided during subsequent visits. The patient education plan is thus divided into three general phases: introductory education, follow-up education, and on-going education. Included with both written and one-on-one verbal communication are audiovisual and group discussion materials which may be introduced when appropriate.

I. Introductory Patient Education

Purpose: The initial visits with the patient (and family when possible) should cover the diagnosed disorder and emphasize its biological basis and key symptoms. Prescribed medications should be clearly discussed, including basic information regarding the purpose of the medication, directions for use, beneficial effects, and potential side effects. The patient should also be given information and tools to monitor symptoms and side effects of medications.

Mode: Initial education should be conducted one-on-one with the patient (and family members, if possible).

Materials: Use the Introductory Patient Education, including Information about the Illness ①, Medication Information ②, and Symptom and Side Effect Monitoring and Coping ③ materials.

Process Guidelines: This is the time to work on developing a good relationship with the patient (and family, if possible) and it should not be rushed. Keep in mind that patients come to the clinic with various cultural and ethnic backgrounds. Some patients may view mental illness and treatment differently than the “traditional Western” perspective. It is possible that some patients will seek alternative treatments, such as those provided by *curanderos*. Information that patients may relay to the physician about alternative treatments should be listened to respectfully.

If the patient is newly diagnosed and it is his/her first experience in the mental health system, allow time for the patient to process information that you are providing and to ask questions. The physician and clinical coordinator should be particularly sensitive to the ramifications that receiving the diagnosis will have on the individual's life. With patients who have been previously diagnosed, ask what they know about the illness and then work from their knowledge base. Be sensitive to the fact that the patient may be frustrated with prior misdiagnoses or unsuccessful

medication trials.

Ideally, initial education should be conducted with the patient and family members. Patients who are not accompanied by family members should be encouraged to consider allowing them to be included in the treatment process. This idea should be reinforced in the first few visits, especially with patients who are very ill and may not retain information. The benefits of family involvement should be explained (e.g., family education leads to better understanding and support, family members' may be better able to retain information regarding treatment at early stages). Patients who report family conflicts related to their illness should be informed that family stress can lead to poor treatment outcomes. Improving family members' understanding of the illness and working together may ultimately improve tense family relations. However, assure patients that their privacy will be respected, even if it means denying family involvement.

If patients refuse to involve family members with their specific treatment, families can receive general information about symptoms, medications and side effects, and the process of treatment, including a description of basic services. Printed material can be placed in the waiting rooms, mailed to a home address, and provided at the visit.

In all cases, patients and families should be given a sense of hope that the illnesses can be treated and managed. Support group information ⑥ can be provided at this time or at any time deemed appropriate.

Physician's Role: The physician should keep in mind that his (her) role may be perceived differently by people from various cultures. For example, some individuals may consider the physician the only authority in the health care system. Therefore, the physician should keep in mind that information/instructions provided by him or her may be taken more seriously than if provided by others (e.g., nurses, social workers, etc). **This is why the diagnosis and medication information should be provided and clearly explained by the physician.**

The physician should explain the diagnosis in laymen's language, using the Disorder Fact Sheet ①, tying in the patient's experiences and symptoms of the disorder. The patient should understand that he/she has a disease, as do those with diabetes or high blood pressure, and that the disease has not been caused by something the patient has (or has not) done. Further, the patient should understand that the illness can be treated as effectively as other illnesses.

It is also imperative that the physician provide the initial introduction to medication alternatives and treatment plans, making use of the specific medication materials (MedCoach Sheets and Medication Benefit Sheets

②). The physician should consider explaining, or going over, the appropriate medication algorithm, if the patient is interested or if it will help explain treatment strategy.

Finally, the physician should introduce the clinical coordinator and explain his/her role to the patient and family members. The physician should also encourage the patient and family to take part in the educational services offered by the clinical coordinator.

Clinical Coordinator's Role: The clinical coordinator should reinforce information provided by the physician, repeat key illness and medication information, address unanswered questions, and serve as the patient's primary contact person. By reiterating and augmenting information, the clinical coordinator develops the patient's perception that both health care providers and the patient work as a team.

After the initial visit information is provided, the clinical coordinator should introduce the patient to the symptom and side monitoring effect sheets ③ (and accompanying materials on coping suggestions) emphasizing that this is not a "pass/fail" test, but a tool to help the patient become more aware of his/her symptoms and to remember what to tell the doctor at the next visit. Rather than stressing the importance of the information, the clinical coordinator should stress the value of the patient's feelings and observations. Explain that the information is "helpful" and "important," but not "critical" or "necessary."

While explaining how to use the symptom/side effect monitoring sheet, the clinical coordinator should consider filling out a sample sheet with the patient to help him/her gain a good understanding of how to use the form.

The clinical coordinator should also inform the patient that bringing the filled-out sheet to the next doctor visit is a good way of informing the doctor how he/she has been doing. In this manner, the doctor can make adjustments to treatment if the patient is not responding as expected.

II. Individual Patient Follow-Up

Purpose: To provide enough additional information to ensure that patients understand the disorder, why it is important to follow the treatment plan, and what they can do to cope with and manage their illness.

Mode: One-on-one with patient (and family, if possible).

Materials Used: Basic Disorder/Treatment Information ④

Roles: The physician will continue to provide information regarding medication treatment, monitor progress, and respond to questions. The clinical coordinator will continue to provide education materials and answer questions.

Process Guidelines: When the patient returns to the clinic, the patient's self-assessment of symptoms and any side effects should be discussed. As the patient's clinical status allows, any changes in symptoms and expectations about treatment should be discussed. Side effects and how they will be managed also should be discussed.

Patients should be provided additional information about their illness (Basic Disorder/Treatment Information ④) at this time and should be walked through the material section by section. Encourage patients to read the material over when they get home and to share the material with family members.

Also encourage the patient to ask questions regarding the disorder and treatment and to seek support from support groups ⑧, if appropriate. The patient should be given reinforcement with respect to benefits of treatment and the importance of self-monitoring and self-help, as discussed above.

Again, the involvement of family, or other significant individuals in the patient's life, should be encouraged when feasible. Explain to the patient that sometimes patients do not notice side effects or improvements, while family members or friends may notice. Tell patients that others' involvement can be helpful in their treatment, but is not "necessary" or "critical." If family members are involved, ask if they have noticed improvements in symptoms and/or side effects. Family members may also find the symptoms and side effect sheets ③ useful.

III. On-Going Education

Purpose: As the patients' symptoms and functioning improve, more extensive educational interventions should be attempted to more fully involve patients in their own treatment and self-care, to foster therapeutic alliance, to help patients and their families find ways to improve quality of life, and to define the goals of recovery.

Mode: These may involve both individual and group interactions. Further discussion of Group Education will follow in section IV.

Materials Used: More In-Depth Materials ⑤, and Videos ⑥.

Roles: The clinical coordinator has primary responsibility for planning and conducting the continuing education. The physician will continue to encourage and answer questions.

Process Guidelines: At each visit, and at additional scheduled education sessions (as needed), the patient should receive more detailed explanations regarding the course of the illness, etiology, physiology of illness, non-drug treatments, and lifestyle management. Again, patients should be walked through materials, so that they understand what information the materials provide and how they are useful. More In-Depth Materials ⑤ can be given to the patient or family at this point, with appropriate discussion and questions answered at subsequent visits.

Patients may want to view videotapes about their illness ⑥ by themselves or with family members (either in clinic or checked out for home use). However, patients should be encouraged to view the videotape in a group of individuals with the same disorder. Each videotape has been structured so that it can be used as a tool to stimulate discussion about what it means to have the disorder. It is often very helpful to understand that other people have had similar experiences. Guidelines to facilitate discussion for each video are provided in this manual.

The timing and extent of the educational process needs to be individualized based on the patient's clinical status, desires, and level of comprehension. For example, the sequence of presentation of each set of educational materials should not be viewed rigidly. In some cases, particularly if the patient does not read, it may be useful to show the videotape earlier in the sequence than noted here. The educational needs of the family, and the rate at which education is provided, may also differ from the patient's. Patients and family members should be encouraged to ask the clinical coordinator and physician questions as they arise.

IV. Group Education

Purpose: The group setting can be used for delivery of new information, but more importantly, for exchange of experiences, problem-solving, and diffusing misconceptions and false beliefs that people have about mental illnesses and their treatment. Perhaps most importantly, consumers can often offer one another a source of hope and support in dealing with their disorder.

Mode: Group setting with facilitator and co-facilitator

Materials: Videotapes ⑥ and Consumer-to-Consumer Group Discussion Materials ⑦

Roles and Process Guidelines: Educational groups are optimally co-facilitated by the clinical coordinator and a mental health consumer and/or family member with appropriate training. In this co-facilitation, the clinical coordinator serves as a "content expert," while the consumer does most of the active group facilitation. Ideally, a group should consist of 15 consumers at most. Smaller groups are conducive to more open group interaction than a larger group would be.

There are many options for educational interventions during the groups.

- (i) The appropriate video ⑥ can be used to facilitate discussion. Written materials are available with suggestions for questions or discussion topics at appropriate break points during the videos. (See Video Discussion Materials Section)
- (ii) An overhead slide educational package ⑦ is available to address important information and common questions and misconceptions regarding mental illnesses and its treatment. (Guidelines for use of these materials are in the Consumer-to-Consumer Discussion Materials Section). Questions to stimulate discussion accompany each overhead, along with guidance regarding major ideas the overhead was intended to impart. The particular set of overheads and support material to be used at each session should be selected and reviewed by the group facilitators prior to the session. The next section of this document (which provides guidelines for facilitating groups) should be reviewed with co-facilitators to assist them in their role.
- (iii) During the consumer-to-consumer discussion group periods (overhead slide package), the clinical coordinator should leave the group and allow the patients and the consumer facilitator to interact. This provides an opportunity for exchange of information and feelings that some patients may have been hesitant to reveal to clinical staff. At what point the clinical coordinator should leave and which materials (chosen from ⑦) will be used during the clinical coordinator's absence should be

decided upon prior to the session.

- (iv) Patient group members should be asked about side effects or other problems they may be having with their medications. Interacting in this fashion allows the offering of appropriate self-help advice, or when necessary, referral to the physician for further evaluation. This is an opportunity to reintroduce materials distributed in prior sessions regarding specific medication side effects and side effect monitoring (②,③).
- (v) Patient members should be encouraged to exchange information in the group regarding experiences they have had with respect to medication response, both positive and negative. This can be a source of hope to patients, and other patients may note improved symptoms in an individual, thus offering a source of encouragement. This also offers an opportunity for exchange of information, hints regarding handling mild but troublesome medication side effects, suggestions for methods to remember to take medications, as well as suggestions regarding non-medication related management of the disorder (including promotion of healthy lifestyles).

It is extremely important at all group discussions that the clinical coordinator and co-facilitator stress the confidentiality of the discussions. However, the clinical coordinator should inform the group that suicidal or homicidal feelings expressed by a patient will be shared with the patient's doctor.

Co-Facilitator Guidelines to Communication and Facilitation Skills

(source: NAMI, Presenter Training Manual for NAMI's "Living With Schizophrenia" Consumer Education Program)

A. What does it mean to facilitate a group?

The role of the group facilitator is both challenging and rewarding. In the most simple terms, to "facilitate" is to make something easier or to help something move along more smoothly. This would mean that a group facilitator helps make the work of the group move with ease. Being the facilitator of a group is different from being the leader, or president, or chair. These positions are assigned and carry with them the authority to exercise control over the group members.

A facilitator empowers a group to do its work itself. One of the signs of a good facilitator is when the group "engages" and the facilitator becomes "just another group member." As a facilitator, you will not be asked to control other group members or to be responsible for ensuring they are helped. You will be asked to complete particular tasks and use specific skills that will allow the group to work together to achieve its goals.

B. Communication Skills

Good communication skills are important to the facilitator. They aid him/her in empowering the group to do its own work. Two skills key to being a good facilitator are the use of "I-statements" and "reflective listening." An example of an I-statement is "I feel ____ when ____ occurred." The use of I-statements defuses potentially volatile situations by stating a response rather than telling someone what he/she did to you. Reflective listening means validating other people's feelings and accepting them as legitimate. Reflective responses that validate others helps the group run more smoothly. Responding in a reflective manner encourages group members to share their own experiences by creating a sense of emotional safety. Reflective responses require that you listen closely and respond in a genuine and sincere manner. It is important to review these two skills in addition to other basic skills. Communication takes practice on a regular basis.

C. Facilitation Skills

As with communication skills, good facilitation skills enable the facilitator to turn the work over to the group. Your contributions as the facilitator, and as a consumer, will make the program legitimate.

1. Modeling

The way a facilitator conducts him/herself will tell the group members a great deal about how they should behave. What the facilitator does has far more impact than what she/he says. This may be difficult at times, but remember that is why you have a co-facilitator.

Treat others respectfully. By being honest, practicing good communication skills, and being compassionate, you can help set the tone for how members will treat one another.

Show that you are paying attention. Position yourself so you face the group. Smile at different people, listen carefully when someone is speaking, scan the group, and make eye contact when you are seeking a response.

Having a co-facilitator (in this case, the clinical coordinator) will be very helpful. You will find that you and your co-facilitator will trade roles during different presentations. You may be the "lead" facilitator for one meeting and your "co" will take over another meeting. Or you may find that the two of you have different areas of strength and will trade off making comments throughout a presentation.

2. Finding Common Ground

This technique allows a facilitator to use the group as the primary resource rather than positioning himself (or herself) as "answer man." Support groups develop around a common problem or concern. Within the group, however, there will be many different stories. The facilitator can help members find a common ground where they can share their similarities.

3. Self-Disclosure

Part of your job as a facilitator will be to share your experiences as a consumer. However, you need to be careful not to share too much. This would be a breach of personal boundaries, which creates discomfort in everyone. You need to be aware of your boundaries as well as the

boundaries of others. You may disclose your situations, feelings, coping strategies, and/or mistakes as a way of encouraging the group to talk about their experiences. It is not necessary for you to have experienced everything that the audience is discussing to be able to empathize with whoever is speaking. New facilitators often disclose more than is necessary. When you are self-disclosing, keep it short and encourage others to share as well.

4. Handling Disruptive Behavior

There may be times when a group member becomes a problem. The person may be talking too loud or taking up too much of the group's time. You will need to be prepared for this difficulty and practice with your partner how you will handle it. Your response needs to be both tactful and firm.

If a person is taking up the group's time, you may want to say: "I appreciate your willingness to share so much of your story; however, we need to let others have a chance to talk as well."

If a person is becoming too loud, you may want to say: "I don't know if you realize it or not, but you are talking pretty loudly. We can hear you just fine in a quieter voice."

5. Using Silence

There will be times when the group becomes silent. Do not feel as if you need to jump in and fill the silence. Allow some time to pass. Often these silences are needed to process information and emotions.

An experienced facilitator counts to him/herself slowly from one to ten before beginning to speak. Often someone in the group will jump in and fill the silence before you do.

6. Handling Nervousness

When public speaking, it is normal to become anxious and/or nervous. How you work with these feelings will greatly influence the outcome of your presentation. One of the best ways to lessen your nervousness is to be sure you are prepared. You will probably be the most nervous during the first five minutes of your presentation. It is okay to be this way; you just have to learn to work with it. If you practice some relaxation skills, you will find them to be quite helpful. These skills can include:

- a. Slowly inhaling, counting to ten, and then slowly exhaling, again

counting to ten. Do this three or four times in a row. (Be careful not to hyperventilate.)

- b. Becoming aware of your body. Note if you feel tension in your neck, in your arms, between your shoulder blades, or elsewhere. Make a conscious effort to focus on the tight spots, and when you are deep breathing, feel them relax.

D. General Communication Guidelines

- Show respect
- Show that you are paying attention when a patient/family member is speaking with you.
- Maintain good eye contact when communicating with patients and their families.
- Be aware of non-verbal cues from the patient and/or family members. For example, crossed arms may indicate defensiveness, scratching one's head or avoiding eye contact may indicate confusion or suppression of feelings.

Key to Successful Outcomes:

- The patient feels positive about treatment/providers
- The patient understands risks and benefits
- The patient interprets understanding and empathy from physician
- The patient feels/experiences support
- The patient can choose among treatment alternatives

Providers must:

- develop a good relationship with patient/family
- recognize patient has a vital role in decision-making process rather than coerce or disapprove
- be empathetic to frustrations of patient/families

Videotapes

We suggest that you schedule time to show the entire video in one day, perhaps having a break or two mid-way through the video for consumers to stretch legs, get a drink of water, and so forth.

You also should decide whether to:

1. Show the entire video and then discuss it once it's over; OR
2. Stop the tape after each section, and then discuss that section. This allows time for discussion while not overwhelming your audience with too much information.

Setting Up For The Presentation

1. Before each presentation, decide who will be the lead presenter. It is important to take turns to allow both of you the chance to lead.
2. Before arriving at the center, decide who will control the lights and who will control the VCR. Again, switch these tasks around for each presentation so each person has the opportunity to do both roles.
3. Get the video ready for the presentation. Find out where you need to sit to best operate the VCR. Learn how to start and stop the VCR so you can discuss each section without putting the video tape on pause. (If left on pause, the video tape may burn.)

What's With You, My Friend? Images of Depression

If you have just been diagnosed with a depressive disorder such as major depression, you probably are feeling a number of emotions right now. You might be wondering about the symptoms of the disorder. You might feel confused about how an illness such as this one occurs and what causes it. You might be feeling the grief that naturally occurs when someone finds out he or she has an illness. You may feel that your life or the lives of your loved ones will never be quite the same.

The following information will be useful in educating you about the illness of the brain called depression. From watching the video and reading through this information, you will see how those who have experienced the illness have learned to cope with it on a daily basis. This may enable you to gain insight and hope in living with depression.

Depression: The Facts

People of all ages, including children, and from all walks of life are susceptible to depression. The illness does not discriminate between rich people and poor people, or people belonging to certain religions or cultures. However, more women than men are diagnosed and treated, and those ages 25 to 40 years are most often affected.

Depression results from chemical imbalances in the brain. It is not caused by poor parenting nor is it a personality defect. Simply, depression is like other illnesses affecting organs in the human body. The abnormal chemistry of depression causes the brain to work improperly, much in the same way that too little or too much of other body chemicals damage the heart, kidneys, or liver.

Just like people with heart disease may have a serious heart attack, people with a brain disorder will have periods when they experience the symptoms of depression. Stressful life events can trigger depression, such as a divorce or the death of a loved one. In addition, certain chemicals, such as alcohol or illegal drugs, can trigger depression or make it worse.

Play Video Segments #1 and #2 -- Music: "What's With You, My Friend?" and Voices Describing Depression (approximately 12 minutes)

(Stop the tape after the family with the son who committed suicide ends their discussion. Then discuss the following section.)

Symptoms

As the people in the video explain, depression is characterized by a deep, abnormal sadness. One man refers to it as “a cancer of the soul.” Sleep and appetite are often disrupted, as the illness affects a person’s thoughts, feelings, behavior, and body. We heard from people in the videotape who describe feeling grief-stricken, anxious and empty. They had trouble performing simple tasks or making decisions. Things that used to bring pleasure no longer interested them.

You may feel like some of the people in the video did -- like you are in a “deep well;” like “you’re calling for help, but no one is listening.” Or you may feel like a “total wipe out as a human being” and think “What’s the use of trying to get better?” You may have been feeling depressed for so long that you cannot even remember what it’s like to feel normal.

The good news is that depression can be treated. Sometimes people can begin to feel a difference within a few weeks. It is important to remember that depression does not always go away on its own and it is not a sign of weakness if you need to get help. In the video, you heard a man describe that two weeks seemed like almost too long to wait, he was in so much pain. But he chose to get the help he needed, and now he is no longer suffering needlessly.

It is not unusual for people experiencing severe depression to feel so in pain and hopeless that they want to “end it all.” A consumer in the video described feeling this way. One family in the video described their loved one’s suffering. They describe the symptoms of his illness that they saw. From childhood, the man was very sensitive and had problems dealing with anger and stress. He also had sleeping pattern disturbances -- he stayed awake at night and slept during the day. Unfortunately, the man did not receive adequate treatment and eventually committed suicide.

Discussion:

1. What have periods of depression been like for you?
2. Have there been times when you felt like you couldn’t survive another day? When you thought about suicide? Does anyone want to describe how you made it through those days?

*Play Video Segments #3 and #4 -- Descriptions of Getting Better (approximately 8 minutes) and Music “You’re on the Team” (approximately 4 minutes)
End tape, then continue with the following discussion.*

Treatment and Recovery

The good news is that treatment is effective for about 80% of people. Antidepressant medication is the most common method of treating people who are depressed. These medications work by altering the action and distribution of brain chemicals so that the brain can work normally. The medications tend to help symptoms such as sleeping, eating, and energy problems the most. It is important to understand that antidepressant medications do not alter a person's character or solve all your problems for you. They can help you perform better, but they don't make you perfect. It is also important to understand that antidepressant medication is not addictive.

However, it can take a while for some people to find out which medication works best for them. Some people may have to try several medications (or a combination of medications) until they find the one that works best for them. And what works for one person may not work for you, since response varies by each individual. So don't get discouraged if you have to try several medications.

Below are some important things to consider when your doctor starts you on a new antidepressant:

- Remember that it usually takes at least a couple of weeks for any medication to become fully effective, even if it is the right one for you. Therefore, try to be patient when your doctor starts you on a new antidepressant; give the medication the full time before deciding how well it is working.
- Some people experience side effects from antidepressant medication. These side effects are usually temporary and mild. If you experience side effects, your doctor may decrease the dose of your antidepressant medication, prescribe a medication to treat the side effects, or change to another antidepressant drug. Your doctor may also suggest ways that you can help to minimize or eliminate the side effects. It is important for you to discuss with your doctor side effects you may be experiencing, rather than trying to deal with them on your own.
- Keep in mind that it requires some effort and commitment on your part to get better. It takes a "leap of faith" in yourself, the antidepressant medication, and your health care providers. You should not feel uneasy about sharing your concerns about treatment with your doctor. It is okay to re-evaluate how treatment is working for you, and to discuss with your doctor changes that are needed in the treatment plan.
- In the near future, more options will become available. Many new medications are being developed to control symptoms better without causing significant side effects.

- Besides medication, there are other treatments for depression, such as counseling, that you may need. Discuss your treatment plan with your doctor to further determine what your specific needs and expectations about treatment are.

In conclusion, it can be hard for some people to accept their illness and that it can be treated. It is very important to make the “connection between antidepressant medication and getting better.” Many people with a mental disorder need to be treated with medication, just like diabetics or people with high blood pressure. The key points to remember are that relief is often not immediate, and that you may need to try more than one antidepressant before you find the right one for you. Getting better is “a process.”

Discussion:

1. How many of you have talked to your doctor about your medications or their side effects? At every visit, do you tell your doctor how you are feeling and whether or not your medication seems to be helping?
2. Many consumers try several different medications before finding the one that works best for them. Describe what this has been like for you. What has finding the right medication done for you?

Below are topics not discussed in the video, but are good topics for discussion.

Lifestyle Strategies for Coping

There are many ways to cope with and manage your illness. Some suggestions are offered below:

- Continue with your treatment. This includes both medications and therapy.
- Watch for re-occurring signs of depression in yourself.
- Prepare for periods when a relapse occurs. Choose a time when you are feeling well and talk with a few trusted friends or relatives to design a plan that will protect you during those times when you are depressed. Make a contract with them that you will reach out for help when you are feeling down or like you want to “end it all.”
- Learn how to handle stress. Listen to music that relaxes you, practice deep breathing, get involved with hobbies. And exercise -- go for a walk with a friend, go to an aerobics class, ride a bicycle. Regular exercise is good for your body and is a natural stress-reducer.
- Remember to keep your sense of humor. Laughter improves health by causing changes in metabolism and brain chemistry.
- Get involved with a support group.

Discussion:

1. What are some of the coping strategies you use to manage your illness? How are they successful for you?
2. What plans have you made with your friends or family members to help you get through the difficult times with your illness?
3. Are you a member of a support group? How have these groups been helpful?

This may be a good opportunity to share support group listings.

Hopes and Dreams

When you function poorly for a long time, you may start to feel like you can't get better. You can't remember what it is like to feel normal again.

However, you can get better! Once you do, relationships with your family can improve, you will start enjoying your friends and social life again, and you can start working on achieving goals such as returning to school, finding a job, or

developing a relationship. Remember that success can be measured by what you accomplish today. Take a step, and then congratulate yourself on being a little further along in your recovery than you were yesterday. You deserve it!

Discussion:

1. What are some of your future plans? How are you taking part in your treatment to make sure that you achieve those goals?
2. How have your friends and family members (your support system) helped you in setting your goals? How have they helped you achieve your goals? How has your support system helped you live a healthier, happier life?
3. Success can be measured by what you do today. What can you do, or what are you doing, today that will help you to feel successful? What are you doing to make sure that you stay on the road to recovery?

When a Family Member or Friend Has Depression

Those who suffer with depressive disorders count on the love, support, and consistent encouragement of their friends and families to get them through the difficult times associated with the disorder. Here is how you can help:

1. Let them know you really care. Don't judge them as inadequate or evil.
2. Encourage your friend or loved one to get professional help. The first step may be for your friend or loved one to talk with a family doctor, a school counselor, a social worker, or a psychologist.
3. Don't take responsibility for making your friend or family member well or keeping the illness a secret. This secret could be a fatal one.
4. Learn as much as you can about depressive disorders so that you can be a reliable source of information when your loved one is not thinking clearly.
5. Stand by your loved one while they are going through treatment and recovery. Be optimistic that treatment will be successful.

Living With Schizophrenia¹

DARK DAYS

If you have been diagnosed with schizophrenia, either recently or some time ago, you may feel confused or disturbed about the changes in your life. Perhaps you find it hard to believe that you have a brain disorder. You may wonder what has happened to you and whether your life will ever seem “normal” again.

The following material gives you more background information on schizophrenia so you can understand it better. It also will describe the lessons learned by the four people in the video- lessons that could help you, as well.

Schizophrenia: The Facts

Schizophrenia is a brain disorder. It is not a personality defect. It doesn't mean you're a failure. Chemical imbalances in the brain, from unknown causes, produce the symptoms of schizophrenia. Scientists with sophisticated equipment can identify physical differences in the brains of persons who have schizophrenia compared to those who do not.

Schizophrenia is like other diseases that involve altered body chemistry. The abnormal chemistry of schizophrenia impairs brain function in the same way that too much or too little of other body chemicals damage the heart, kidneys, or liver.

Most illnesses have symptoms. For example, people with heart disease often have chest pain. Similarly, people with schizophrenia have symptoms of their illness, like hearing voices, having disorganized thought patterns, or withdrawing from social activities.

The Biological Basis of Schizophrenia

Science has revealed a lot in recent years about what goes on in the brain. Tests have been especially useful in understanding what happens in the brain of someone who has schizophrenia. Magnetic resonance imaging (MRI) tests have shown a structural abnormality in brains affected by schizophrenia. They show a mild to moderate enlargement of certain sections of the brain. Other studies have shown differences in brains of people with schizophrenia, such as a decreased number of nerve cells, or *neurons*, and too much or too little of certain chemicals.

¹ This discussion has been adapted from the NAMI-produced video discussion material for the Living With Schizophrenia video

Causes

The exact causes of schizophrenia are not known at this time, although several theories exist. Because all people who have schizophrenia share similar symptoms, they are diagnosed with the same illness. While a common brain mechanism may contribute to the major symptoms, it is likely there are multiple causes for what we call schizophrenia. Below are factors that scientists have correlated, or have frequently noticed, in people who have schizophrenia. We do not know for sure whether these factors cause schizophrenia. In addition, these factors do not predict whether someone will develop the illness.

Imbalances of brain chemicals: Studies have shown that imbalances in brain chemicals, such as dopamine and serotonin, are present in patients who have schizophrenia. Therefore, one widely-accepted theory says that imbalances in these brain chemicals cause the illness. This assumption has been the basis for the development of many antipsychotic medications, which act by correcting these imbalances.

Genetics: Biological relatives of people with schizophrenia have increased risk for the disorder. In other words, schizophrenia seems to run in families. Therefore, genetics are thought to play a role in the causes of schizophrenia.

Birth factors: Complications during pregnancy and birth are more common among those who develop schizophrenia. In addition, those who develop the disease are 5 to 15 percent more likely to have been born in the winter. We don't yet know how these birth factors relate to the cause of schizophrenia.

It's Not Just You

You may think that your symptoms and experiences are so unusual that no one else understands. You may feel that you're the only person on earth with these problems. In fact, you are not alone. About 2.5 million Americans have schizophrenia, and about 100,000 more people are diagnosed every year. That's a large number of people with problems similar to yours. Though you may not know many of them right now, in time some of them may become good friends.

Difficult Days

The early days of dealing with schizophrenia can be very difficult. The people from the video shared some of their hard times: “I was suicidal and delusional -- it scared me,” said Shannon. She had a college roommate who referred to her as “such a psycho,” which hurt her feelings.

Dylan said, “It was hell what I went through. I had no job, car, or money, and I wasn’t going to school. I had nothing.” His mother recalls that she didn’t recognize him when she first went to pick him up after his breakdown. “There was such an impact on his physical appearance and ability to communicate,” she said.

George had a difficult time, too. “My voices kept telling me , “Your mom is a witch. She’s poisoning your food.” It was so bad I couldn’t eat at the same table with my parents and eventually had to move out.” George’s mother remembers that he used to see demons and talk to them.

Coming Back

The disorder can turn your life upside down, disturbing your plans, and robbing you of precious years and opportunities. However, like Shannon, Dylan, and George, you can regain at least some, and perhaps a great deal, of what you have lost. Although it may be frustrating now, you can come back the way they did.

The first step is accepting the fact that you have a serious brain disorder in need of treatment.

DISCUSSION:

1. How did you feel when you first found out you had schizophrenia?
2. How has your life changed since you were first diagnosed with your illness?
3. Have any of you felt socially isolated because of your mental illness? Has anyone ever called you names, like Shannon’s roommate did? How do you think other people in society view you because of your mental illness?

ACCEPTANCE

Recovery from schizophrenia can be a long, difficult journey. Yet those who have recovered say accepting the reality of having a serious brain disorder was their first step toward being well again.

If you have difficulty accepting the fact that you have a brain disorder, you're not alone. It can be hard for anyone to accept having a serious illness, no matter what the illness is. But as Dylan said, "If you have cancer and don't accept the fact that you have the illness, what would you do?"

While you can't do anything about having schizophrenia, you can do a lot about how you respond to having it. You can make choices that will help you lead the life you want.

The four speakers in the video shared their thoughts about accepting their brain disorders, and how that attitude helped them improve their lives. Their experiences may be helpful to you.

Kathy

Kathy found it difficult in the beginning to accept having schizophrenia. "I couldn't believe I had a mental illness," she said. "I was fighting myself. I was in denial." But she later realized that schizophrenia was something she had to deal with for life. "Once I really came to terms with being mentally ill, I decided that I had to make it part of me and make myself whole -- spiritually, mentally, and physically."

George

George remembers vividly how he came to accept his illness. "When I was in the lockdown unit, I sat down one night and said, 'Wait a minute, George, something's going on here. Either you're going to be in and out of hospitals, or just say that it's okay to be ill, and maybe you can do something to improve your quality of life.'" He realized that when he acknowledged having an illness, he could take steps to improve his life.

Shannon

Communicating what you're feeling to family and close friends can help you accept the illness, according to **Shannon**, and it can help those around you better understand what you're experiencing. "In trying to communicate with my family about my symptoms, I tried to be as direct and clear as possible," she said. "I'd say, 'This is what it feels like. I'm afraid that everyone is talking about me and they are reading my mind. I feel the need to do self-destructive things because I feel worthless. I'm scared and I don't know how to deal with it.'"

Dylan

“You not only have to accept the illness, but accept what you have to do to stay well,” **Dylan** discovered. “Once I accepted it, I did the right things like giving up vices, living healthy, doing different activities, working, and so on.”

No One Is To Blame

Having schizophrenia doesn't mean that there is anything wrong with you as a person. You are still a valuable, worthwhile human being with a lot to contribute to the world around you. This disorder is not your fault or your parents' fault. No one is to blame.

What having schizophrenia does mean is that you need to get appropriate treatment throughout your life. You will benefit from learning new ways to take care of yourself, and you will have to take medication every day to get well and stay well. You can still have a satisfying and meaningful life despite schizophrenia.

DISCUSSION:

1. How did you accept the fact that you had a mental illness? What led you to acceptance?
2. Shannon says that she tries to be direct and clear in explaining her illness to her family. How do you describe your illness to your family? To your friends? To your doctor?
3. Have any of you had to deal with family or friends who can't accept that you have this illness? How has that made you feel?

COPING SKILLS

“Coping skills are developed by basically becoming aware of things you need to know to make your life successful,” says Kathy. “I’m aware of patterns you can follow that help you stay in a very healthy mode of life.” Coping skills help manage the stress associated with daily living. This is especially important for people with brain disorders such as schizophrenia, because stress often plays a major role in causing symptoms to develop. Incorporating coping strategies in your life, recognizing warning signs, and taking prompt action when you notice them can help head off relapse and hospitalization.

The consumers in the video identified several coping skills that helped them manage their day-to-day lives. They should be useful to you, too, and you may discover other coping strategies for yourself.

Develop an active, balanced lifestyle

Living successfully with schizophrenia includes maintaining a **regular schedule** that balances periods of **activity, relaxation, and sleep**. Make sure that your daily life includes adequate time for all three.

Shannon’s best coping strategy is to “make sure that I stay on some kind of schedule and that I don’t have lots of downtime I could use in a destructive way, like worrying or getting worked up.” She works, goes to school, runs a support group, and stays busy. Dylan’s many activities include giving talks on schizophrenia to numerous groups such as university classes. He credits frequent public speaking with helping to restore his confidence. (There may be public speaking opportunities in your area as well.) Kathy also recommends getting into a routine and sticking to it. “Get up at the same time every day. Take your medicine at the same time. Get into a routine and use it as if it is law.” Writing down your schedule can help you stay busy and organized.

In addition, take care of your body. Kathy began to eat right and exercise once she realized she had a brain disorder. Eating good, healthy meals gives your body and brain the fuel they need to operate efficiently. Cut down on junk food and drink several glasses of water each day.

Dylan competes in volleyball and practices martial arts to stay in shape. Find sports or other physical activities you enjoy and can afford. A partner makes it more fun and easier to stick with an exercise program. Regular exercise has benefits too good to pass up, such as increased energy levels, reduced depression and anxiety, improved coping and self-esteem, and better overall health.

Some activities can be relaxing. For example, hobbies can also be a good source of relaxation and personal fulfillment. Dylan, Shannon, Kathy, and George all have hobbies that help them relieve stress and cope. Dylan writes poetry and plays the piano. Shannon studies art and is now an accomplished painter. Kathy is an avid trading-card collector, and George builds models in his spare time.

These leisure activities may give you ideas for hobbies you'd like to pursue. The important thing is to find relaxation activities and hobbies that you are interested in, that help you relax. Activities that come out of your own interests will be the most satisfying and relaxing.

Resting is also a good way to stay healthy. According to George, one of the best ways to cope is to get enough rest each night. "If you start losing your sleep, it means you're headed for a breakdown. So I always watch it. I take my medication at 9 or 10 o'clock each night and then go to sleep." Occasionally an afternoon nap may refresh you if you haven't had enough sleep. If you've been especially busy for some time, you may need to give yourself extra time to rest and recover.

DISCUSSION:

1. What are some of the things you do to manage your illness?
2. Kathy talks about having a schedule to help her manage her illness. Does anyone here have a daily schedule? What is your schedule and how does it help you?
3. Can anyone relate to George's comment about losing sleep? Is this one of your signs that you may be heading for a breakdown? How do you manage your sleeping and waking time?

MEDICATION

The Purpose of Medications in Treating Schizophrenia

“If you have a heart disorder, you have to take medication; if you have diabetes you have to take insulin.” This is Kathy’s approach to the need for medicine.

Since there’s no cure yet for schizophrenia, the goals of medical treatment are to:

- * *eliminate or reduce symptoms;*
- * *minimize side effects;*
- * *prevent relapse and hospitalization; and*
- * *enable the person affected to resume social, work, and school activities.*

Because schizophrenia is primarily a disorder of brain chemistry, medication is necessary to correct the biochemical malfunctioning of the brain. Antipsychotic medications are the foundation of treatment and are critical to achieving these results.

There are additional treatments and ways you can help yourself (see the section on coping strategies). However, if you do not take the right medication(s) at the right dose--consistently-- other things you do will not be enough to keep you healthy.

Important Things to Keep in Mind about Medication

Remember: Medications affect different people in different ways. Since no blood tests are currently available to determine the most beneficial medication, some trial and error is necessary to find the right medication and the right dose.

For example, many antipsychotic medications have side effects which can usually be managed through a variety of strategies, such as reducing the dose, taking the medication at a different time of day, switching to another medication, or adding a medication to counter side effects. It is important for you to communicate with your doctor any problems you are having, rather than trying to deal with side effects on your own.

Sometimes a combination of medications may be necessary to control symptoms of the illness as effectively as possible. Some people take an antipsychotic medication plus an antidepressant and/or an anti-anxiety medication.

In addition, certain stressful events in your life may require “fine tuning” in the medications you are taking.

Regardless of which medication your doctor starts you on, there are several things you can do to help find the right medication (and the right dose) as soon as possible. You can help your own treatment by taking medication as prescribed, and communicating clearly and honestly with your doctor about your symptoms and side effects.

In addition, you should try to be patient. It usually takes several weeks for any medication to become fully effective. Give it the full time before deciding how well it is working. Don't get discouraged if you have to try several medications. Most people can find a medication (or combination of medications) that works pretty well in time. Also, there will be more options available to try in the future. Many new medications are being developed to control symptoms better without causing significant side effects.

George advises: "Even though one medication doesn't work and your side effects are still there, don't give up." Shannon remembers taking 20 different medicines during the course of her illness, but offers this encouragement: "Generally, once the medicine I'm getting kicks in, then in a couple of weeks I'll begin to see the light and things will start getting better."

Kathy says: "If it makes me well, if it makes me function, if it makes me normal -- Yes, I want to take it!"

DISCUSSION:

1. Have you talked to your doctor about your medications and their side effects? At each visit, do you tell your doctor how you are feeling and whether or not the medications seem to be helping?
2. Like Shannon, many consumers try different medications before finding the one that seems to work best for them. Describe what it has been like for you. How do you feel now that you have found the right medications?

SUCCESS, HOPES, AND DREAMS

Living successfully with schizophrenia is possible. The four consumers in the video demonstrated that in sharing how they came back for their “dark days” to create lives that are satisfying and meaningful. You too can build a rewarding life you feel good about.

Success means different things to different people. While entering or completing college might be long-term goals for some consumers, maintaining steady employment or volunteer work could be a key objective for others. Developing a circle of good friends, having a nice, comfortable home, and simply staying as well as possible can all be measures of success.

Whatever your own hopes and dreams are, the strategies that George, Kathy, Dylan, and Shannon use to help them stabilize their lives are a good place to start. They accept their illness, take daily medications as prescribed, and use coping skills to guide them through stressful days. Their dedication and systematic approaches to recovery have helped them achieve many of their goals.

Suggestions for Creating Success in Your Life

Consumers come from different backgrounds, have a variety of skills and ambitions, and approach life in their own particular ways. One key to recovery is remembering that you are a unique individual with your own needs and desires.

However, certain aspects of recovery are common to all people who have mental and physical disorders. As mentioned, accepting your illness, taking daily medication as prescribed, and using coping strategies for managing stress are basic steps that provide the foundation for moving forward and accomplishing your goals.

Start small, then build on early successes. Set realistic, attainable goals. In the beginning, your activities may involve just handling your daily living needs, like shopping, cooking, doing laundry, or cleaning your home. Later you can add a wider range of activities. As you feel better, you can think about volunteer work, a regular job, going to school, or other major goals. Break larger goals into more manageable steps. Accomplishing each step will give you confidence to go on to the next one.

Set your own goals, pursue your own dreams. Decide what you really want from life. You’re the only one who can determine what success means to you. Dreams from before you developed schizophrenia may still be possible, perhaps with some changes. You may discover new interests because of your experiences of living with a brain disorder. Many consumers, including the ones from the video,

incorporate what they've learned from their illness into their activities and plans for the future, such as helping other people with similar disorders.

Be determined, yet patient. While working consistently toward your goals is important, remember that patience is necessary too. Recovery doesn't happen over night. Even if you have setbacks or feel discouraged from time to time, your determination to stay as healthy as you can will help you make progress toward accomplishing the things in life that are most meaningful to you.

DISCUSSION:

1. What are some of your future goals? How are you taking part in your treatment to make sure that you achieve these goals?
2. How have your family and friends (your support system) helped you in setting your goals? How do they provide support in achieving your goals?
3. Remember that success can be measured by what you do today. What can you do, or what are you doing, today that will help you to feel successful?

DARK GLASSES AND KALEIDOSCOPES

Definition

If you have just been diagnosed with bipolar disorder, you are probably feeling a number of emotions right now. You might wonder about the symptoms of the disorder. You might feel confused about how an illness such as this one occurs and what causes it. You might be feeling the grief that naturally occurs with the prognosis that accompanies a chronic mental illness. You may feel that your life or the lives of your loved ones will never be quite the same.

This information will be helpful in giving you an education about the illness of the brain called bipolar disorder. By observing those who have experienced the illness and have learned to cope with it on a daily basis as provided in the video and reading through this information, you may be able to gain insight and hope in living with bipolar disorder.

Bipolar Disorder: The Facts

Bipolar disorder results from chemical imbalances in the brain. It is not caused by poor parenting nor is it a personality defect. Simply, bipolar disorder is like any other illness of an organ in the human body. This one, however, involves body chemistry. The abnormal chemistry of bipolar disorder impairs brain function in the same way that too much or too little of other body chemicals damage the heart, kidneys, or liver.

Just like people with heart disease may have a serious heart attack, people with a brain disorder will have periods when the illness rears its ugly head, and they experience the restlessness of mania or the deep lethargy which accompanies a depressive episode.

Symptoms

Tony Dow, the narrator of the video, compares the illness to somewhat like having two pairs of glasses. One pair “turns the world into a marvelous kaleidoscope...a center of high energy and excitement.” The person who wears these glasses can feel on top of the world “for a while.” This is a manic state and it is a period of intense energy. The individual feels that he/she is highly creative and has no need for sleep. The manic state can be very pleasant to the person who is experiencing it. However, after these intense and exciting periods, things can change drastically and a person can experience a period of deep sadness. A feeling of worthlessness and hopelessness may replace the ecstatic highs of mania. The kaleidoscopes are replaced by dark glasses.

Mania

As Kim shares in the video, mania for her was a feeling of invincibility, “I had no worries. I could do anything on very little sleep...there’s just endless possibilities in mania.”

The common symptoms of mania are:

- Increased energy, activity, restlessness, racing thoughts, and rapid talking
- Excessive “high” or euphoric feelings
- Extreme irritability and distractibility
- Decreased need for sleep
- Unrealistic beliefs in one’s abilities and powers
- Uncharacteristically poor judgment
- A sustained period of behavior that is different than usual
- Increased sex drive
- Abuse of drugs, particularly cocaine, alcohol, and sleeping medications
- Provocative, intrusive, or aggressive behavior
- Denial that anything is wrong

Dr. McElroy describes periods of mania as “characterized by changes in mood that include euphoria, feeling extremely happy...happier than you ought...feeling expansive, feeling elated ...also along with that is profound irritability.” It is easy to understand how powerfully seductive mania can be for those who experience it.

Depression

The most common response to the depressive state of bipolar disorder seems to be the need for sleep. Kim and Lori in the video both stressed the overwhelming desire to sleep and the utter exhaustion that overwhelmed them. A lack of motivation to do the simple things in life, such as eat, disrupts daily living. Lori shared that “at the worst point was the constant obsession with death.” Life doesn’t seem worth living anymore when a person is in an advanced state of depression. This is when the illness can become life-threatening.

(PLEASE STOP THE TAPE after Lori says, “The places I go are so bad that I just can’t be there, again.”)

DISCUSSION:

1. What have periods of mania been like for you?
2. If any of you have had times when you have hurt yourself or others during a manic state, can you share that with us?
3. What is it like for you immediately following the mania?
4. How are Kim or Lori’s experiences similar to yours? How are they different?

(PLEASE START THE TAPE)

Forms of Manic Depressive Illness

Just as with any other illness of the body, bipolar disorder has differing levels of severity and takes on a variety of forms. Both doctors in the video talk about these different forms of the illness.

There is a milder form of mania called hypo-mania, which is characterized by mild feelings of euphoria, mild periods of increased energy and a decreased need for sleep. However, this form is not nearly as disruptive to an individual's ability to work or socially interact.

A mixed state of the illness is when an individual is experiencing depressive symptoms and manic symptoms at the same time. One doctor stated that this is a particularly "uncomfortable" state to be in because the individual has "the symptoms of agitation, racing thoughts, and increased energy associated with mania" and they feel depressed at the same time.

Perhaps the most common form of bipolar disorder is Bipolar Type 2. This is when people have big depressions and milder mania. Sometimes the mood swings can happen rapidly. Andrew shares that "these cycles of activity and depression were beginning to come closer together and they were getting more intense." In a severe case of mania, a person can lose touch with reality and may experience psychotic symptoms where they may suffer with delusions or false beliefs.

Suicide is a real temptation to the person who has bipolar disorder. It is estimated that 60-80% of all adolescents who commit suicide have a history of depression. About 15% of all people who suffer with the illness take their own lives. "It's an immense tragedy," as Tony Dow states, "because manic depression and depression are among the most treatable diseases."

(PLEASE STOP THE TAPE after Tony says, "It's an immense tragedy because depression and manic depression are among the most treatable diseases.")

DISCUSSION:

1. Can any of you share the forms of the illness discussed above (such as hypomania, a mixed state or rapid cycling) that you have experienced?
2. Have any of you ever thought about or attempted suicide while you were depressed? Can you relate to Lori's experience with depression? To Andrew's?

(PLEASE START THE TAPE)

Causes

According to research, we have no definitive cause for manic depressive illness. However, we know of two factors which contribute to its predisposition:

- Genetics
- Periods of extreme crisis, grieving, or financial strain

The most encouraging fact about the illness is that it is highly treatable and that medications can help to prevent relapses.

One of our video's doctors declares the importance of staying on medication. He says that "people can be vulnerable to recurrences of manic or depressive episodes even if there don't appear to be obvious or stressful events in their lives. That makes it particularly critical that people stay on their meds and in treatment even during periods when it seems like everything is going reasonably well in their lives."

Probably the most difficult step to take is to accept that one has this illness. For Louis in this last section, this was his greatest hurdle to leap. His spouse recognized that something was wrong and tried to talk with him about it. However, everything was "fine as wine," according to Louis.

We know that at this time there is no cure for this disorder, but as Tony says, "In real life we like to talk about treatments." The first step to getting on the right track to treatment is to accept that there is an illness in your body which is affecting the way you think and feel.

(PLEASE STOP THE TAPE after Tony says, "...who's up to date on the latest medications and who understands the importance of monitoring your progress.")

DISCUSSION:

1. When did you first realize that you had a mental illness? Did you experience anything while you were growing up that made you sense that something wasn't quite right?
2. What was most difficult for you in accepting that you had the illness? How do you feel about it, now?
3. Have any of you had to deal with family or friends who can't accept that you have this illness? How has that made you feel?
4. Tony Dow mentions that many who suffer with the illness thought that their minds worked better or that they were more creative during their manic episodes and that these are reasons that many did not seek treatment. Do you think this is true? Having gone through the illness, as many of you have, and

then finally gotten treatment, what would you say to the person who chooses not to get treatment for these reasons?

(PLEASE START THE TAPE)

Medications and Treatments

As mentioned earlier, manic depressive illness is one of the most treatable diseases. According to statistics, 80-90% of those who seek treatment see a significant decrease in symptoms and an observable improvement to the quality of their lives. As Dr. Keck states that treatment includes as a cornerstone, medications for mood stabilization.

There are many medications available now that work, well. Many more medications, which will work even better will soon be available. Consumers need to be patient in finding the right medication that will work best for them. This requires trial and error many times, and that is why it is so important to talk to your doctor if the medication you are taking is not helping you.

We have many examples in the video which illustrate how successful the right medications can be for treating this illness. Lori shares that her medications for her mania put her where she needed to be and that the meds have given her a normal life, again. For Kim, when the meds finally started working, "there was a light that went on." She states, "My head was finally clear enough so that I could make plans for myself and my future."

We know that medications have a positive effect on our well-being. Once some people start feeling better, their first reaction is to stop taking their medications. With a chronic illness, this is not a wise thing to do. Tony Dow compares it to correcting vision with glasses. Different people need different prescriptions, but they all have the chronic problem of less than perfect vision. Lori says, "If you had an ulcer or if you had diabetes, you would do what the doctor says. Why is this medication any different because it deals with the central nervous system?"

Not following treatment usually means you will get sick, again. Art has firsthand experience of what effect not following treatment has on his ability to handle his illness.

"Two or three times I decided to stop the medication because I was feeling better and as anyone, no matter what condition you have, you feel like you can live without the medications...that you don't need to take them. I had this attitude and I would stop and I would go into a mania or a depression."

(PLEASE STOP THE TAPE after Dr. McElroy says, "People who have bipolar disorder who have the illness treated have life spans as long as those without the illness.")

DISCUSSION:

1. Have you talked to your doctor about your medications and their side effects? At each visit, do you tell your doctor how you are feeling and whether or not your medications seem to be helping?
2. Many consumers try several different medications before finding the one that seems to work the best for them. Describe what it has been like for you. Lori and Kim describe the effects of the right medication as “causing the head to clear” or like “a light went on.” How do you feel now that you have found the right medication?

(PLEASE START THE TAPE)

Lifestyle Strategies for Coping

Within the video there are many suggestions given about managing one's illness. It is true that we can't change the fact that we have an illness, but we can take responsibility for our own treatment programs.

Tony Dow, who copes with manic depressive illness himself, offers these suggestions:

- Continue with your treatment. This includes both medications and therapy.
- Watch for re-occurring signs of mania or depression in yourself. Watch for anger or combative or erratic behaviors.
- Keep a journal every day and track your overall mood. This will help you understand the cycles of your illness.
- Prepare for periods when a relapse occurs. Develop a plan for what you will do if you start to think about suicide. Write down the warning signals and keep them handy for yourself.
- Choose a time when you are feeling well and talk with a few trusted friends to design a plan that will protect you during those times when you are manic or vulnerable to ideas that you would never consider in a normal state.
- Learn how to handle stress. Listen to music that relaxes you or practice deep breathing.
- Exercise. This is a natural stress-reducer. Take a walk, go for a bike ride, jazzercise!
- Avoid situations which may trigger a relapse.
- Remember to keep your sense of humor. Laughter improves health by causing changes in metabolism and brain chemistry.
- Get involved with a support group.

The other consumers in the video share coping strategies that are successful for them.

Lori:

- A wonderful support system of good friends
- Daily walking
- A daily routine

Kim:

- Exercise
- Eat healthy foods
- Stay away from drugs and alcohol
- Maintain a well-balanced life with friends and family
- Avoid isolating yourself
- Communicate with your doctor
- Get involved with a support group

Andrew:

- Periodic visits with the doctor
- Get involved with a support group

Every single one of the consumers mentioned involvement in a support group. With the support of others who are going through the same experiences, everyone can gain strength and become better at managing their own illnesses.

(PLEASE STOP THE TAPE after Kim's father says, "No one meeting Kimberly would ever know she has this illness.")

DISCUSSION:

1. What are some of the things you do to manage your illness? How are they successful for you?
2. What types of plans have you developed with your friends or family members to help you get through the difficult times with your illness?
3. Are you a member of a support group? How have these groups been helpful?

This may be a good time to share the list of local support groups ⑧.

(PLEASE START THE TAPE)

Hopes and Dreams

Art has an excellent philosophy of living. He says about his illness, "some people call them disabilities. I call them gifts. You can turn some of the gifts we have into productive things...Think about the things you can do as opposed to the things you can't do."

For some of you, once you are feeling better you may want to return to school, find a job or get married. Remember that success can be measured by what you accomplish today. Take a step, and then congratulate yourselves on being a little further along in your recovery than you were yesterday. You deserve it!

(PLEASE STOP THE TAPE AT THE END OF THE VIDEO.)

DISCUSSION:

1. What are some of your future plans? How are you taking part in your treatment to make sure that you achieve those goals?
2. How has your support system helped you in setting your goals? What part has it played in your life to make sure that you live a healthy one?
3. What have you done to make sure that you stay on the road to recovery? What plans have you made to make sure that you continue to follow your dreams?

WHEN A FAMILY MEMBER OR FRIEND HAS BIPOLAR DISORDER

Those who suffer with manic depressive disorder count on the love, support, and consistent encouragement of their friends and families to get them through the difficult times associated with the disorder. Here is how you can help:

1. Let them know you really care. Don't judge them as inadequate or evil.
2. Encourage your friend or loved one to get professional help. The first step may be for your friend or loved one to talk with a family doctor or a school counselor or social worker or a psychologist at a community mental health center.
3. Don't take responsibility for making your friend or family member well or keeping the illness a secret. This secret could be a deadly one.
4. Learn as much as you can about manic depressive illness so that you can be a reliable source of information when they are not thinking clearly.
5. Stand by them when they are going through treatment and recovery. Be optimistic that treatment will be successful.

Consumer-To-Consumer Group Discussion Material

The overheads are a collection of drawings made by consumers that depict common issues regarding mental health treatment from the consumer's perspective. These drawings are meant to facilitate discussion in a group forum about these issues, as a means to reassure, educate, and support consumers.

The consumer facilitator should be responsible for taking the lead during discussion sessions. It may facilitate better discussion among the consumers if the clinical coordinator (or other staff) is not present during all or some of the discussion session, but is available should the consumer facilitator need assistance. Ideally, the purpose of the overheads is to encourage consumers to talk among themselves about personal experiences and beliefs, without being concerned about possible reactions from staff. The discussion is meant to provide consumers with self-help and coping strategies and also learn from one another.

The facilitator of the discussion group should review the overheads prior to the group discussion session. The overheads have been categorized into 11 topics, or sections, to be presented over six sessions:

Session I

- A. Diagnosis and Treatment;

Session II

- B. Medication Therapy (general messages);

Session III

- C. Monitoring Medication Side Effects and Treatment Progress;
- D. Keeping Track of Your Medication Schedule;

Session IV

- E. Why Some People Don't Take Their Meds;

Session V

- F. Communicating With Your Doctor - Why You Should;
- G. Communicating With Your Doctor - Why Some People Don't;
- H. Communicating With Your Doctor - Problems Some People Have;
- I. Communicating With Your Doctor - How To;

Session VI

- J. Suicide and Life
- K. Families

A brief description of each topic (section) follows. In addition to the description, thoughts about what each cartoon is attempting to convey and questions to stimulate discussion are available in the Peer Facilitator Guide.

Brief Descriptions of Each Section

Session I

- A. **Diagnosis and Treatment - 2 overheads**
This section provides information on how consumers are diagnosed and who they can talk to regarding their treatment.

Session II

- B. **Medication Therapy - 6 overheads**
This section provides information about medication in general and from whom consumers can get medication information.

Session III

- C. **Monitoring Medication Side Effects and Treatment Progress - 5 overheads**
This section stresses the importance of self-monitoring and informs consumers of common side effects.
- D. **Keeping Track of Your Medication Schedule - 4 overheads**
This section illustrates ways to remember medication schedules and the possible consequences of non-adherence to medication regimens.

For example, one overhead shows a person who has just crashed his car. The caption says that the consumer's "Meds Journal" showed that he hadn't taken his medication since Friday. This overhead illustrates that a medication journal can help patients remember what they did and can help them evaluate the relationship between their medication use and changes in their emotions, behavior, and thinking. The person in the cartoon doesn't understand what has happened, but is able to observe in his medication journal that he missed several doses of medication.

Another overhead shows a woman writing on her medication use chart, with a child developing her own chart. This overhead demonstrates that some people need visible reminders to take their medication. Reminders can be a note on a calendar or an elaborate chart.

Session IV

- E. **Why Some People Don't Take Their Meds - 8 overheads**
There are multiple reasons why people choose not to follow their medication regimen. Some reasons are false beliefs about the medication, side effects or characteristics of the medication that they don't like, or fears that the medications will alter their appearance or behavior. This section can be used to help dispel myths or false beliefs, as well to openly discuss realistic concerns that consumers may have about taking medications.

Session V

- F. Communicating With Your Doctor - Why You Should - 2 overheads
This section shows reasons why consumers should be honest and open about their therapy, mainly because doctors cannot read minds and often don't notice issues until the consumer brings them up.
- G. Communicating With Your Doctor - Why Some People Don't - 3 overheads
This section illustrates common reasons why people don't talk to their doctor. Some concerns that patients have are that they don't want to be admitted to the hospital, or don't want to add or change medications.
- H. Communicating With Your Doctor - Problems Some People Have - 3 overheads
Sometimes consumers may feel that their doctor talks down to them or talks in medical terms, which can be confusing. This section depicts consumers experiencing poor communication.
- I. Communicating With Your Doctor - How To - 1 overhead.
This single overhead shows a consumer talking with his doctor. Ideally, both people should be on "equal levels," discussing therapy plans and progress in an open, honest manner.

Session VI

- J. Suicide and Life - 2 overheads
This section deals with feelings of suicide and provides multiple reasons why one should reconsider.
- K. Families - 7 overheads
Family members often don't understand the mental illness that afflicts their loved one. This section depicts several common family scenarios.

PEER FACILITATOR GUIDE

Please keep in mind that the following material is only a suggestion of how you might approach discussion of the overhead transparencies. Try to have the group lead the discussion, but if needed, you can prompt a discussion using your own ideas, or by using the following examples. Also note that people in the group may have other interpretations of the cartoons which are equally as valid as those given here.

SESSION I

Topic A. Diagnosis and Treatment

Objectives

1. Define the purpose of the DSM-IV.
2. Provide options for support for consumers who are in crisis or experiencing symptoms.
3. Define "personal support system."
4. Assist consumers in recognizing and naming individuals who are a part of their "personal support system."

Materials You Will Need:

- Transparencies - #1, #2
- A copy of the DSM-IV
- The Symptoms/Side Effects Sheet or the Disorder Fact Sheet
- Paper and pencils (optional)

Introduction

Good morning (afternoon/evening), and welcome to our first group discussion. My name is _____ and I will be our group facilitator. Let me tell you a little about myself before we get started.

Note to co-facilitator: Take some time to briefly share your story and explain why you are sitting in the facilitator's chair today. Try to limit this to 3 minutes.

Transparency #1

An accurate diagnosis is very important to the treatment of our mental disorders. Once an accurate diagnosis is made, we can begin taking the necessary steps to get better, including selecting the most appropriate treatment.

There is a process that every doctor follows in determining a diagnosis. The Diagnostic and Statistical Manual of Mental Disorders (also called DSM-4 for short)

is the book that doctors use in making a diagnosis. The DSM-4 describes the symptoms associated with each mental disorder. The manual also talks about how a diagnosis is made. You may not have all the symptoms listed in the manual. I have a copy of the DSM-4 with me today, if you would like to look at it.

Let's take some time to look at the symptoms that are associated with your diagnosis of (major depression, bipolar disorder, schizophrenia). I have copies of the information you may have received a while ago that list the symptoms of (major depression, bipolar disorder, schizophrenia).

Note: Distribute the Symptoms/ Side Effects Sheet or the Disorder Fact Sheet. Ask the consumers if they would like to share their feelings about these symptoms.

Discussion questions for Transparency #1:

Who has experienced these symptoms?

Which ones have you experienced?

Transparency #2

Here are some examples of people who can give you support or assistance. **Note:** *Discuss the examples on the overhead projector.*

There are different kinds of support that we may need as we go through life dealing with our illness. Sometimes we may have questions about our meds or our symptoms, so we go to our doctor or clinical coordinator or pharmacist. These people act as our *informational support*. We may have others, like a friend or case manager, who give us *instrumental support* by providing assistance, like transportation to our appointments or to the grocery store. In addition, we get *emotional support* from our friends and family who will listen and try to help. We have different kinds of relationships with the people in our support systems, so they may support or help us in different ways.

Discussion questions for transparency #2:

Who wants to tell us about their support system?

How do these people help you?

Do you go to different people for different kinds of support?

Note: *If no one in the group has much to say about this transparency, you may wish to share your own personal support system. For example, you might say, When I need help I will turn to my doctor, or to my sister, or my caseworker. These are some of the people who make up my personal support system. I usually go to my doctor when I have questions about side effects of my medication (informational support), but I may talk to my friend if I want to talk about a problem at work (emotional support).*

SESSION II

Topic B: Medication Therapy

Objectives:

1. Emphasize the importance of taking medications as prescribed by the doctor.
2. Assist consumers in identifying the correct resources (doctor, nurse, pharmacist) if they have questions about medications.
3. Explain that patience is essential when waiting for prescribed medications to take effect.
4. Stress that self-medication or experimentation with their medications can cause serious harm to the treatment process and to their physical and mental health.
5. Emphasize that mixing alcohol, street drugs and their medications can be dangerous and deadly.

Materials Needed:

- Transparencies - #3, #4, #5, #6, #7

Today we are going to take time to discuss the importance of taking our medications properly so that our treatment is more likely to be successful.

Discussion questions for transparency #3:

Are you able to take your medications on a routine time schedule?

What helps you to remember to take your medications?

Discussion questions for transparency #4

Who have you talked to in the past about your medications?

Have you ever asked friends or family members when you have had questions about your medications?

Who do you think would be the most helpful in answering your questions?

Do you ever have questions about your medications that you never ask anyone about?

Note: After discussion of the transparency, or if no one in the group is discussing the transparency, you might add:

Sometimes an activity or a late meal alters our routine, and we are unsure whether we have taken our medications at the right time or if we have taken them at all. We

might ask, “What happens if I miss a dose?” or “What happens if I mistakenly take two instead of one?” When we have questions or concerns such as these, it is important that we ask the people who can give us the most accurate answers. These people would be our doctor, our nurse, our clinical coordinator or our pharmacist.

Discussion questions for transparency #5

Have you ever experienced this period of waiting for your medications to work?

What was it like for you?

Did you do anything while you were waiting that helped you?

Note: *After the group has discussed the transparency, you might add:*

Most medications do not work right away. It can often take weeks before you will begin to feel the results. Have patience, don't give up hope and don't stop taking your medications without talking to your doctor or nurse first. If you need encouragement or support in getting through those first few weeks, talk to your clinical coordinator, other consumers who've been through the same experiences, friends, or family members.

Note: Be sensitive to the possibility that some people may have been through many medication changes and are truly discouraged. If you want to, you can add:
You can also talk to me after the session, since I have been through this before.

Discussion questions for transparency #6

Ask what this message means to the consumers. If no one knows, try to facilitate a discussion that addresses these points:

The message in this transparency is that self-medicating or sharing your prescriptions with friends or family members can be extremely dangerous. It is unhealthy for you to take medications that have not been prescribed for you or to mix certain medications or to take too much of certain medications.

Discussion questions for transparency #7

Is anyone willing to share his or her feelings on this transparency?

What is the message here?

Has anyone had an experience like this that they'd be willing to share?

Note to co-facilitator: If no one in the group is commenting on this transparency,

you might say: This transparency illustrates that alcohol, street drugs and your medications don't mix, so it is best to avoid the alcohol and street drugs, or at least speak with your doctor about the effects of mixing alcohol or drugs and your medication.

Ending: Thank you all for taking the time to share your experiences today. Next time we are going to discuss how to monitor medication side effects and your treatment progress.

SESSION III

Topic C: *Monitoring Medication Side Effects and Treatment Progress*

Objectives:

1. Discuss the Symptom/Side Effects Sheet and its usefulness for daily monitoring.
2. Emphasize the common side effects of medications.

Materials Needed:

- Transparencies - #8, #9, #10, #11, #12
- Symptoms/Side Effect Sheet

Discussion questions for transparency #8

Let's take a couple of minutes to talk about how we feel today. Who wants to tell us what this transparency means? Where are you today on this chart?

Note: *You might add:*

Keeping track of how you feel daily helps you and your doctor know if your medications are working for you or not. Monitoring helps you stay aware of small changes or progress from day to day.

Discussion questions for transparency #9

What side effects have you noticed from your medications?

What do you do when you feel those side effects?

Note: *Mention the self-help sheets that were given to you by your clinical coordinator for side-effect management. You can say that this side effect management sheet may be beneficial in helping consumers deal with specific side effects.*

Notice that some of the most common side effects of medication include nausea, thirstiness, sleepiness, agitation, shakiness, headache, diarrhea, blurred vision, light-headedness. You should be aware of the different kinds of side effects your medication can cause. Your doctor should have given you information on your medications that probably listed the common side effects. If you don't have this information, please see the clinical coordinator after our meeting today, and we can help you get it.

Discussion questions for transparency #10

Have you ever experienced drowsiness while working or driving a car due to your

medications? How do you cope with it?

Note: *After discussion of the transparency, you might add:*

Always read the warning labels on your medications and take them seriously. If your label says, "Don't drive while taking this medication...may cause drowsiness," it is important to be aware that you could feel some drowsiness, especially in the early stages of taking this medication. In fact, drowsiness is a common side effect. If drowsiness due to medication is a problem for you, talk to your doctor about how you can adjust your activities or ask your doctor about another medication (especially if the drowsiness interferes with your work).

Discussion questions for transparency #11

Coordination can also be affected by your medications.

Have any of you felt clumsy at times due to your medications?

How do you deal with it?

Discussion questions for transparency #12

Sometimes our visual perceptions will be altered by our meds. We may see halos around lights, for example.

Have any of you experienced this side effect? How do you manage side effects that interfere with vision?

Note: *After the group has talked about this transparency, you might summarize what has been discussed, such as:*

It can be very helpful to track your symptoms and side effects on a daily basis. When you can sit down with your doctor and show him or her your monitoring sheet, this helps to give an accurate picture of how you are feeling. Your doctor can then modify your current medication dose or perhaps provide you with a more effective medication. Overall, your doctor can give you better care and you will feel better.

Thank you all for sharing your experiences with your side effects. It helps all of us to have a clearer understanding of how medications work.

Topic D: Keeping Track of Your Medication Schedule

Objectives:

1. Illustrate the method of using a pill tray to keep track of medications.
2. Explain “medication journal” and how to use this method for remembering medications.
3. Explain a medication chart and how to use this method for a visible reminder.

Materials Needed:

- Transparencies - #13, #14, #15, #16
- Pill tray
- Calendar or TMHC Medical Notebook (that we provided)

Discussion for transparency #13

Sometimes it can be difficult to remember whether you have taken your medication.

Having a method of keeping track of medications is important. Each of us has to find what is the best method for reminding ourselves to take our meds.

Have you had difficulty remembering whether or not you have taken your medication?

What do you do to keep track of what medications you have taken?

Discussion for transparency #14

Today we are going to take some time to discuss different methods for establishing a medication reminder that works for each of us.

A pill tray or box is an inexpensive and easy way to know if you have taken your medications. There are pill trays for every kind of dosage...three-times-a-day or one-time- a-day. You can find one at your pharmacy. If you have children, please make sure that you get a childproof one.

Have any of you used a pill tray before?

Note: *It may be helpful to have samples of pill tray to show the group. Take time to discuss how effective this reminder method is.*

Discussion for transparency #15

What happened in this cartoon?

Note: *After discussion has ended about this transparency, add:*

One way to remember what medications you have taken is a medication journal or calendar. Sometimes looking back over your medication journal can help you understand why you might be feeling “out of sorts” or having accidents (maybe you missed several doses of medications). Have any of you tried using this method?

Note: *Some may be unfamiliar with this method. You may want to illustrate with the TMHC Medical Notebook or a calendar.*

Discussion for transparency #16

Keeping a visible reminder, such as a chart, can also be a helpful way of keeping track of your medication use. This transparency is not suggesting using your child as a reminder. However, having a chart that is visible to everyone around you can be helpful.

Have any of you tried this method?

Was it helpful?

Note: *Take some time to discuss all the methods and reinforce the helpfulness of having a reminder.*

I hope that you have all gotten some ideas about a method for remembering your schedule that will work for you. It may help to use two methods at the same time so that you will always have a back-up. You may need to experiment with the different methods to find the one that works with your lifestyle. Whatever you choose to do to assist you in remembering to take your medications will be beneficial in the long run.

SESSION IV

Topic E: *Why Some People Don't Take Their Meds*

Objectives:

1. Assist the group in setting realistic expectations for managing their illness.
2. Emphasize the difference between “street drugs” and medications used to treat an illness.
3. Explain that it is more beneficial to manage side effects than to go without medication and try to manage the illness.

Materials Needed:

- Transparencies - #17, #18, #19, #20, #21, #22, #23, #24

Discussion for transparency #17

Some of you may have felt that taking medications on a daily basis gets old and frustrating. We know medications help with the symptoms, but they are not the cure for all of our problems. Like the person on this transparency, there are some things about us that medications are not going to fix. Some people expect the medications for their illness to take care of all of their problems and quit taking them when they don't.

Have you ever quit or felt like quitting your medications because they weren't helping you in all the ways you expected?

Discussion for transparency #18

Many people worry about gaining weight and it is true that some medications cause weight gain. Have you ever experienced this fear or had this experience?

It is important to talk to your doctor about this side effect. There are alternative medications available if this is your concern. Also, your doctor may be able to provide you with ways to control your weight.

Discussion for transparency #19

As children, some of us were told to keep away from medicine because it was “bad” and could hurt us. We sometimes carry these feelings and messages into adulthood. As adults, however, we recognize that medications are needed to treat illnesses and, as long as they are taken as prescribed, are not “bad” for us.

As a child did you get the lecture that medication was bad and should not be touched?

How do you feel about that message as an adult?

Discussion for transparency #20

Some medications taste bad or leave a taste in your mouth. Remember, you can take medication with juice or put a mint in your mouth right after taking it to eliminate that taste.

Discussion for transparency #21

Another message some of us may have learned is that “drugs” are dangerous, costly, or only for sickly people. Let’s take a couple of minutes to talk about these messages.

How do you feel personally about having to take medications?

Have you ever tried to stop taking your medications? How did you feel, then?

Remember...medications for your illness are **not** the same as street drugs.

Discussion for transparency #22

Some medications have side effects that make you feel uncomfortable. You may worry that people will notice and you may feel a little self-conscious. Have any of you ever felt this way? You can do a reality check with a friend you trust. Ask him or her whether the side effects of the medications are noticeable.

Remember to talk with your clinical coordinator or doctor about your side effects.

Discussion for transparency #23

Sometimes when you are ill (particularly manic), it feels good for a while. It may be hard to take medication that temporarily makes you feel worse (or takes away those “high” feelings). However, even if you feel really good for a while, you are likely to end up feeling bad. Do you remember what it was like to feel psychotic or extremely depressed? It is **not** fun!

Have you ever felt like you wanted to stop taking your meds, like when you are manic, in order to experience that “high”?

What do you do when you feel this way?

Discussion for transparency #24

Some medication regimens are difficult to follow. Sometimes it is hard to keep up with taking medications more than once a day or taking more than one medication.

In short, some medications are just “hard to swallow.” People who need insulin every day probably feel the same way.

Note: *This cartoon can also be taken literally, because some medications are actually hard to swallow.*

Have any of you ever experienced this? How did you cope?

Even though there may be many reasons to not take our medications, most often the positive effects of medications outweigh the negative. They can truly help us to feel better. So it is important to follow our daily routine of meds.

Thank you all for sharing your experiences. We continue to learn from each of you who participate with us in our discussions.

SESSION V

Topic F: *Communicating With Your Doctor - Why You Should*

Objectives:

1. Emphasize that communicating with the doctor brings faster relief.

Materials Needed:

- Transparencies - #25, #26, #27, #28

Discussion for transparency #25

What does this transparency mean to you?

There are many side effects that you may feel, but go unnoticed to the rest of the world. Often your doctor doesn't notice unless you tell him or her. What seems obvious to you may not be so obvious to other people. That is why it is so important to keep track of your side effects and symptoms and be sure to tell your doctor. An easy way to do this is to bring your Symptom/Side Effects Sheet with you when you visit with your doctor.

Discussion for transparency #26

What does this transparency mean to you?

Do you feel safe talking to your doctor when you are not feeling well? Why or why not?

What are your fears?

Your doctor or clinical coordinator can only help you if you tell him or her how you feel.

Discussion for transparency #27

People are often afraid that if they tell their doctor they are feeling bad or not feeling better they will be put in the hospital or given more medications.

Have you ever felt this way? Has this ever happened to you in the past?

Discussion for transparency #28

Does this look familiar to anyone? These are common fears that many of us feel.

They are normal fears. However, for things to get better we must always be straightforward and share with our doctor or clinical coordinator when we aren't feeling well.

Topic G: *Communicating With Your Doctor - Why Some People Don't*

Objectives:

1. Stress that fear of changing medications can become a barrier in recovery.

Materials Needed:

- Transparencies - #29

Discussion for transparency #29

It is very true that changing medications can be scary. You may be afraid of getting sick again or that the new medication won't work. Starting over again can be scary even if you haven't gotten much better on your old medications.

Let's take some time to discuss how changing medications has affected us in the past.

What has it been like for you?

Topic H: *Communicating With Your Doctor - Problems Some People Have*

Objectives:

1. Emphasize that communication with the doctor brings faster relief and recovery.

Materials Needed:

- Transparencies - #30, #31, #32

Discussion for transparency #30

Sometimes it seems like doctors are unapproachable or intimidating.

Have you ever felt like this in the presence of your doctor? How did it affect your relationship with your doctor?

Discussion for transparency #31

Sometimes it seems as if doctors speak a foreign language that only other doctors

understand. Or they may say so much in a short time, it is difficult to process all the information. Keep in mind that you can ask a doctor to write the information down for you. You may also ask them to repeat or explain something that you don't understand. It is your right to know and understand everything you can about your illness.

Have you ever had an experience like the one shown here? How did you handle it?

Discussion for transparency #32

Medications have more than one name - there is the brand name like Tegretol and a generic or chemical name like carbamazepine for the same medication. Also, the generic medication may look different than the brand-name medication, which can really be confusing. If you are not sure you have been given the right medication, ask your doctor or pharmacist.

Topic I: *Communicating With Your Doctor - How To*

Objectives:

1. Emphasize that communicating with the doctor should be done as equal partners in the treatment process.

Materials Needed:

- Transparencies - #33

Discussion for transparency #33

Discussions between you and your doctor should be on an equal level...not like the "big doctor, little patient" transparency I showed you earlier. You should be a helpful partner in your treatment process.

Do you feel comfortable talking with your doctor as equals? What is your relationship with your doctor like? Can you describe it?

SESSION VI

Topic J: *Suicide and Life*

Objectives:

1. Explain that there has been tremendous progress in understanding how the brain works and in treatment for mental illness in the past decade; that many new medicines are being developed.
2. Emphasize that there is reason for hope if old treatments haven't worked in the past.
3. Recognize that waiting, getting through the hard times, is very difficult, and takes courage and determination.

Materials Needed:

- Transparencies - #34, #35

Today we are going to talk about a sensitive issue...one that many of us may find difficult to discuss. However, many of us have experienced at one time or another, that there is no hope and we might as well just give up.

Discussion for transparency #34

Have you ever felt hopeless about finding a treatment that will work for you? How did you deal with this feeling?

Even if you feel like there is no hope for getting better, realize that new medications are coming out much more frequently than in the past. One of these new medications may work for you even when others you have tried haven't.

Discussion for transparency #35

We may all feel a little uncomfortable with this transparency because it talks about suicide. Suicidal thoughts can be a sign or a symptom that your illness is getting worse. It is important to talk about it openly. It is also important to understand that you don't have to act on it. Because this can be a very stressful and confusing time, others have found that preventive planning can help (such as agreeing to tell a special friend when you are having suicidal thoughts).

Let's look at the transparency, again. Notice the suggestions that surround the person who is having suicidal thoughts. These suggestions have been helpful to some people in keeping them from taking action on suicidal thoughts.

The most important message is "**DON'T!**"

Topic K: FamiliesObjectives:

1. Describe how family members go through many of the same stages as we, as consumers, do in coping with the illness, such as denial, guilt, etc.
2. Emphasize the importance of encouraging family members to become educated about the illness.
3. Explain that children need to be educated, as well.
4. Emphasize the importance of support groups for family members to help them cope with the illness.
5. Explain how open communication with family members will help them to understand the illness and what we, as consumers, are feeling.

Materials Needed:

- Transparencies - #36, #37, #38, #39, #40, #41, #42

Discussion for transparency #36

Just like we do, family members go through many emotions in trying to cope with and accept our illness.

Sometimes family members have a hard time accepting that you have a mental illness. They think it can't happen in their family and they may feel ashamed because of the stigma that is attached to the illness in our society.

Does your family refuse to accept or believe that you have a mental illness? Or did they feel that way in the past?

What helped them accept your illness? How has this improved your relationship and communication with them?

Discussion for transparency #37

Family members are sometimes blamed for your illness and they think that it is their fault you are ill. This guilt is a heavy burden for them and it hurts them to think they may have caused you harm in some way.

Has your family ever felt responsible for your illness? How does this affect you?

Education about mental illness often helps family members to accept your illness and to support your recovery. Classes and support groups are available for families in many areas, such as those provided by the Texas Alliance for the Mentally Ill. (*Make reference to local area referral list*).

Has your family received any education about mental illness? Did this help? Does your family know that help is available?

Discussion for transparency #38

What is happening in this cartoon?

What do your family members or close friends think about your taking medications? Do they try to push their beliefs on you? How does this affect you?

Without education, your family members and friends may try to help in the best ways they know how. Sometimes the things they suggest are not helpful, such as seen here. Accepting that you need medication can be hard for your family, just as it might have been, or still is, for you.

Discussion for transparency #39

Children, especially young children, do not understand mental illness. They just expect you to be “mommy” or “daddy”.

For those of you who have children, how do your children react when you are sick? How do you deal with this? Can you provide examples of the ways you have dealt with your children that might be helpful for others to try?

It is at these times when other family members (like a spouse or a parent) can help. Remember to use your personal support system during these times.

Discussion for transparency #40

Ask the group what this transparency means. If they don't know, say:

This shows another reaction that children may have when mom or dad gets sick. Have you ever had to deal with this? What did you do?

Discussion for transparency #41

Often family members have unrealistic expectations about treatment. They might think that if you take a pill or go to the hospital, you should be back to normal right away. This can be stressful for you.

What are your family's expectations about your treatment? How do their expectations affect you?

Once again, it is a good idea to suggest to your family members to become educated about your illness and the recovery process. Encourage them to attend a class or a support group, or provide them with some of the pamphlets you've been

given about your illness.

Discussion for transparency #42

There are times when family members think they can “snap you out of it” when you are sick. Sometimes they assume that if they act bright, bubbly and optimistic, so will you.

Do your family members or friends (or coworkers) do this? How does it make you feel? How can you respond to this?

The important thing to remember is that, just like you, family members need education and support in order to understand and cope with the illness. Once everyone has the knowledge, it makes for better communication and stronger relationships.

Closing: Does anyone have any questions about the things we have been talking about? Does any one want to add anything? Are there issues that you feel are important that we haven’t discussed? If so, can you share what they are? Do you feel this group discussion has been helpful to you? How?

*After discussion has ended, thank every one for coming and participating. **You might say:***

This has been a support-oriented educational group to complement your medication treatment. If you think you would benefit from an ongoing mutual (or peer) support group, here is a list of some groups available in this area (provide support group referral list). A peer support group would be less structured than this group and would offer more opportunities to discuss these kinds of issues with people who have mental illnesses like yours. There are also support groups for family members, such as those available through the local Alliances for the Mentally Ill.

QUESTIONS AND ANSWERS ABOUT THE CONSUMER-TO-CONSUMER DISCUSSION GROUPS

What is the purpose of the Consumer-to-Consumer Discussion Materials?

The Consumer-to-Consumer Discussion Materials were created by consumers of mental health services to stimulate discussion between consumers about their illnesses and treatment. The materials touch upon issues from the point of view of consumers that are often not included in formal educational materials about mental illness, and often not openly discussed. Through discussion of these topics consumers will learn more about self-management of their illnesses and treatment from the experiences of other consumers.

Are the group meetings supposed to be run like therapy or support groups?

First, the groups are NOT, in any way, intended to be therapy groups.

While the groups will have a “peer support group” element to them, the intent of the groups is primarily educational. Each session will revolve around a particular topic or topics. The nature of the discussion will be oriented, to some degree, to the content of the cartoon overheads. It is expected and intended that there will be personal sharing (and thus “support”) around the topics. However, we expect the discussions to be somewhat more focused than they would be in a pure support group.

How many consumers should we have in a group?

In part, this will depend on the number of consumers interested in the program. You made decide after three interested consumers to go ahead and start the sessions. On the other hand, you may have five or more interested in attending. Smaller groups may do better, as far as discussing issues openly, and we recommend that you limit your group size to 10 to 15 at most.

How should the group session be scheduled?

The Consumer-to Consumer Discussion materials have been grouped into six sessions. Within those sessions, there are one or more topics or sections. Please see the Peer Facilitator Guide in the Patient Education Plan Guidebook for details. We have estimated that each session should last approximately 1 to 1 ½ hours. We suggest that you present each of the six sessions separately, perhaps one session per week. Some groups may be able to spend two hours or more and go through two sessions at a time. However, scheduling will depend on multiple factors, including how long consumers prefer to discuss the materials (some may not want to have sessions lasting more than an hour or so), how many consumers are interested in participating, when you have an available conference room, what your schedule is like, and so on.

Some individuals may wish to attend the sessions more than once, particularly

because of the support element. This may be especially true in areas that do not have peer support groups. We do not see a problem in allowing TMAP consumers to attend as many sessions as they wish.

How do we deal with “special situations,” such as suicidal threats or verbal and/or physical aggression?

The clinical coordinator and consumer co-facilitator should develop a plan of action for special situations, such as suicidal threats or aggressive behavior. These plans should be consistent with center regulations and should take into consideration consumer respect, dignity and the overall welfare of the group. Confidentiality does not apply to situations that jeopardize the welfare/lives of consumers.

More questions: Call Marcia Toprac, [\(512\) 206-5465](tel:5122065465) or Terri Conner [\(512\) 206-4629](tel:5122064629)

Patient Education Activities Log

Instructions for Completing the TMAP Patient Education Activity Log

General Instructions: One line of the TMAP Patient Education Log is to be completed each time the TMAP physician, clinical coordinator, or patient education group co-facilitator utilizes a portion of the TMAP patient education package with a patient. A line should be completed for scheduled education activities, as well as for education provided during a normal scheduled clinic visit. If a group education activity is conducted, one line should be completed for each patient present. Two examples of entries have been provided on the activity log on the next page.

Local Case #: The unique case number assigned to the patient by the local community mental health/mental retardation center. This number is used on all TMAP forms.

Site/Clinic #: Site number is the three-digit component code assigned to this community center by TDMHMR. The clinic number is a one digit number assigned to the specific clinic by TMAP.

Date: Date on which the educational activity took place, in the form of mm/dd/yy.

Provider: Use one or more designated codes on each line to indicate who carried out the educational activity or provided the material. If the activity is conducted by more than one provider together (e.g., the clinical coordinator and a family member) only one line should be completed, with both provider codes listed. If two providers (physician, clinical coordinator) provide education to the patients separately on the same day, fill out separate lines for the activities of each provider.

Recipients: Use one or more of the designated codes to indicate the direct recipients of the educational materials or activity. Only one recipient code should be used on each line.

Time: The time spent on an activity should equal the total time the patient (or family) spent on an activity. [For example, if two facilitators conduct a group discussion together for twenty minutes, the total time experienced by the patient would be twenty minutes of group discussion.] Indicate the amount of time the educational activity lasted (in five minute intervals). If educational material was just handed to the patient (or others), time should equal five minutes.

Materials Used: List the codes associated with all materials used or provided during this educational interchange.

Complete a line of this form for each patient education activity performed during the week until a page is complete, then start a new page. At the end of your work week (Friday afternoon or Monday morning), enter your name, provider code, date (on which the forms are FAXED) and page number at the bottom of each page and FAX to the Data Center. Start a new page at the beginning of the next week to avoid sending duplicate data.

