



FAMILY EDUCATION WORKSHOP

Manual

Family Institute for Education, Practice and Research

A partnership between The New York State Office of Mental Health and the University of Rochester Medical Center, in collaboration with the Conference of Local Mental Hygiene Directors and NAMI-New York State

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FAMILY EDUCATION WORKSHOP

CLINICIAN MANUAL

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FAMILY EDUCATION WORKSHOP

CLINICIAN MANUAL

Chapter 1. Introduction

A. Rationale and effectiveness.

The purpose of the Family Education Workshop (FEW) is to provide information about schizophrenia, bipolar disorder and other severe and persistent mental illnesses. The same clinicians who have joined with family members and lead ongoing problem-solving groups also lead the FEW.

Leaders should behave openly and collegially and identify an agenda shared by family members, clinicians, and consumers. While this manual focuses on schizophrenia, you should have information about bipolar disorder, schizoaffective disorder, personality disorders, and addictive disorders available for family members. If you are using this treatment for groups where the focus is a disorder other than schizophrenia, then you will need to make appropriate adjustments.

We recommend you start with refreshments and socializing. Begin the education workshop saying something like this:

(SUGGESTED CLINICIAN REMARKS)

Thank you for coming today to the Family Education Workshop at _____(name of your clinic or agency). We are pleased that you are able to join us in working together for the recovery of your family member from schizophrenia/bipolar disorder/mental illness and we want to help you participate in your relative's treatment and recovery. While our focus is on schizophrenia, we will present information on other mental illnesses and make printed information available to you.

Information about schizophrenia/bipolar disorder/SPMI is important to

clinicians, consumers, and family members. Information helps us to understand mental illness, to know what to expect, and how to help in the healing and recovery process. We want every one, consumers, family members, and clinicians to share the same knowledge base so we can work toward the same goals in recovering from mental illness.

These are complex illnesses that look different in different people and are confusing for many. The more information you and your consumer/ relative have, the better equipped you'll be for problems and unexpected events. We will also discuss guidelines for coping with the mental illness that other family members have found helpful.

The education workshop is only one step in our family treatment process and only one part of your family member's comprehensive treatment plan/service plan. After this workshop we will meet in groups of family members every 2 weeks to continue providing information, developing, trying, and evaluating solutions to problems you tell us are important, and providing a social network that supports your relative's recovery.

We have found that having a common knowledge base and working together in problem-solving groups with consumers, family members, and clinicians has beneficial effects:

- a. Consumers have fewer relapses and less severe relapses when they do occur.**
- b. Consumers experience more satisfaction with overall treatment.**
- c. Consumers attain more of the goals of their treatment plans.**
- d. Family members are more satisfied with treatment their relative receives.**
- e. Family members experience less stress and worry.**

(END OF SUGGESTED CLINICIAN REMARKS)

It is helpful to have points (a) to (e) where everyone can see them. Consider these options:

- (a) Newsprint,
- (b) Whiteboard,
- (c) Printed and included in participants' folders.
- (d) Powerpoint presentation.

You should then review the schedule of the day with families. The schedule should be available so everyone can read it at the same time you review it. (See section 5, Handouts for Families, Family Education Workshop Schedule).

You may want to have parts of your introduction on newsprint, whiteboard, or powerpoint so family members can read along with you. Before you conduct the workshop read the sections of this manual on creating a classroom format. Here is a sample review of the schedule:

(SUGGESTED CLINICIAN REMARKS)

As you can see, we have a full schedule with lots to cover. We will talk about the causes of mental illness, the experiences of consumers with mental illness, guidelines you can follow to help with recovery, and what we think are realistic expectations of treatment. We will try to give both scientifically based-information and practical advice on our experience and the experiences of other families.

(END OF SUGGESTED CLINICIAN REMARKS)

Chapter 2. PREPARATION AND PLANNING

A. Establishing a Classroom Format

Clinicians should establish a classroom format for the Family Education Workshop in order to help reduce family members' anxiety and communicate that the goal of the workshop is educational rather than therapeutic.

Means to creating a classroom format:

- Place chairs auditorium-style or around a table.
- Use a blackboard, whiteboard, or newsprint pad to write participants' questions, draw diagrams, and provide information in a visual format.
- Give each person who attends a folder containing printed materials and blank paper for taking notes.
- Tell participants the structure consists of lectures and question and answer periods.
- Tell participants this is not therapy or venting.
- Use videos, movies, or tapes.

B. Options: Time, Place, Interdisciplinary Teaching

Time

You can hold the workshop as a single meeting or over several meetings. You should expect the workshop to last about 7.5 hours in the all-day format, with 6 hours of formal instruction, and breaks for lunch and refreshments.

Providing the Family Education Workshop in several meetings is possible; we suggest no more than 3 meetings of 2.5 hours each. You may decide to provide the Family Education Workshop in multiple meetings in order to accommodate clinician schedules, distribute workload appropriately, or to bill for more of the time you spend with families. Since the longest time you may bill for a meeting is 2 hours, if your FEW is an all-day

meeting you will need to forego billing for part of the services you offer. You may decide to hold a single all-day meeting because you want families to spend more time together, transportation is more easily arranged, or you believe information is transmitted more efficiently in a single meeting.

Place and Equipment

A classroom setting works best for providing information. You will need a VCR player and something to write on. Materials for participants should include:

- folders
- printed schedule
- printed handouts
- blank paper for taking notes
- pens or pencils

Interdisciplinary Teaching

Having different members of the treatment team attend the FEW helps family members get to know everyone, learn the roles of different treatment team members, and reduces the pressure on any individual clinician to present all the material included in the Family Education Workshop. It's better to have several presenters who are experts in different areas than one person covering many areas superficially.

Family members benefit from meeting treatment team members outside of their professional roles, so the opportunity to socialize with family members is part of the family psychoeducation treatment process.

C. Practice Presenting Information

Most clinicians have not been trained to present information to groups of people. As a result, nervousness about making presentations during the Family Education Workshop is

a normal response. Fortunately, nervousness usually decreases with preparation and practice. Steps clinicians can take to prepare to lead the Family Education Workshop:

1. Preparation of materials

- A. Review written materials, videotapes, audiotapes ahead of time.
- B. Write your presentation in the format that is comfortable for you: word-for-word or outline. If you are unfamiliar with public speaking you will need to spend some time practicing your presentation.

2. Practice public speaking

- A. Give your presentation, alone, either in front of a mirror or video camera. Videotape or audiotape your presentation and listen to yourself afterwards.
- B. Give your presentation with colleagues who will both support you and give you helpful feedback.
- C. The Family Services Coordinator may need to help organize the speakers practice sessions, including the best way to give each other feedback.

D. Family Education Workshop: Suggested Schedule

- 9:00-9:15: Coffee and Informal socialization
- 9:15-9:30: Formal introduction and explain format of the day
- 9:30-10:30: The phenomenology of the illness
Etiology, course, and outcome of the illness
The private experience of schizophrenia
The public experience of schizophrenia
- 10:30-10:45: Coffee break and informal interaction
- 10:45-12:00: Treatment of Schizophrenia
Medication
How it works
Why it is needed
Impact on outcomes
Side Effects
Psychosocial Treatments
Wellness Management & Schizophrenia
Health care
Diet
Stress
- 12:00-1:00: Lunch and informal socialization
- 1:00-3:30: The family and schizophrenia (mental illness/bipolar disorder)
Needs of the patient
Needs of family members
Family members reactions to serious mental illness
Emotional responses
Behavioral responses
Common problems that families and patients face
What families can do to help
The Family Guidelines
The problem-solving process
- 3:30-4:00: Questions about specific problems
Description of the MFG process
Patience with the slow pace of improvement
Keeping hope alive
Wrap-up, scheduling

Chapter 3. MATERIALS FOR TEACHING ABOUT MENTAL ILLNESS

A. Introduction to *Schizophrenia Explained*

The video by William McFarlane, M.D., entitled *Schizophrenia Explained*, (labeled January 1999, Length 1 hour) covers some of the material clinicians need to present in the Family Education Workshop. We recommend you show sections one through six of the video during the morning workshop section, and section seven the first part of the afternoon session. Show each part, followed by questions and discussion. The video and the sample clinician remarks in this manual are complementary, so you may mix and match clinician remarks and video presentation in the order that meets the needs of your participants.

Chapter 5 of this manual, entitled "Discussion Guide for *Schizophrenia Explained*," describes each section of the video, summarizes the contents, and suggests discussion questions.

B. The Five most Important Messages

There are five important messages that you need to communicate to families during the Family Education Workshop. These are the basic points the workshop curriculum covers. Families often do not grasp them immediately and you need to find ways of repeating them at different points in the workshop in different words. You will need to continue repeating them during the problem-solving groups after the workshop.

THE MOST IMPORTANT MESSAGES

1. Families are not to blame for mental illness. Families do not cause mental illness.
2. The clinicians' goal is to work in partnership with families.

3. Schizophrenia/bipolar disorders are brain-based illnesses.
4. Adherence to medication is the key to treatment and recovery.
5. Recovery from SPMI/schizophrenia/bipolar disorder is possible.

C. The Experience of Schizophrenia

Hearing about the experience of mental illness helps family members to understand how their relative is affected by the illness. This manual includes some samples from published first-person accounts of schizophrenia but you may use others to illustrate the experience of schizophrenia for consumers. Since learning is more effective if learners are exposed to multiple media, make the table below available on newsprint, PowerPoint, or overhead projection screen and put it in participants' folders.

(SUGGESTED CLINICIAN REMARKS)

We start this workshop by establishing a common understanding of the mental illness called schizophrenia. We will also talk about other mental illness today.

Instructions to clinicians: Start "Schizophrenia Explained" and show sections one, followed by discussion, then section two, followed by discussion.

This table adapted from Anderson, et. al. (1986, p. 86) is a useful way to begin talking about the experience of schizophrenia. It is found in your folder.

Personal Experience

Distraction

Overload

Sensitivity

Misperceptions

Public Manifestation

Thought disorder

Delusions

Hallucinations

Social withdrawal and apathy

Distraction

Paying attention is our most basic cognitive skill. Without the ability to give our attention to something, we are unable to learn about the external or internal world, form perceptions, or store information in memory. Without perception or memory, we are unable to form a coherent conception of self.

Here are some consumer's descriptions of distraction:

- “I couldn't read the newspaper because everything I read had a large number of associations. I mean, I just read a headline and the headline would have much wider associations in my mind.” (Freedman, 1974, p. 335)
- “I jump from one thing to another. If I am talking to someone they only need to cross their legs or scratch their heads, and I am distracted and forget what I was saying.” (McGhie & Chapman, 1961, p. 104)

Distraction results from the consumer's impaired ability to screen out distracting stimuli from the stimuli he/she is trying to attend to. A person with attentional problems as in schizophrenia cannot direct his/her attention to a speaker, a book, or an object. Instead, perceived things intrude on the person's attention.

- “I am speaking to you just now, but I can hear noises going on next door and in the corridor. I find it difficult to shut these out and it makes it more difficult for me to concentrate on what I am saying to you. Often the silliest little things that are going on seem to interest me. That's not even true; they don't interest me, but I find myself attending to them and wasting a lot of time this way.” (McGhie & Chapman, 1961, pp. 104-105)

While the personal experience is distraction, attempts to tell someone about all of this don't hang together or follow logical or chronological order. The public experience is thought disorder: loose associations, bizarre speech patterns.

Overload

People with schizophrenia generate internal stimuli that competes for attention with external stimuli. The mind's "switchboard operator" is unable to keep track of all the different stimuli, resulting in consumers losing the ability to keep track of items in logical or chronological order. When the internal "switchboard operator" breaks down, patients attach beliefs to inappropriate things, so the experience of overload results in what we external observers of people with schizophrenia perceive as delusions.

Sensitivity

Many consumers tell us that the qualitative character of their experiences change so that colors seem brighter, sounds louder, sensory images more vivid, and familiar objects have ominous or threatening meanings associated with them. When combined with the increased number of associations due to distraction and overload and the confusion due to the inability to sort and track stimuli, this increased intensity of qualitative experience makes the world seem more distressing to patients.

Misperceptions

With all the impairments of attention, stimuli, and sorting, it is easy to see how patients begin to misperceive reality. Things that patients know are stable and stationary start moving, ordinary objects appear disconnected or start coming together in bizarre ways, or gestures intended to be comforting appear eerie or anxiety provoking. This internal arousal often leads patients to withdraw from social contact that provokes such distressing experiences.

(END OF SUGGESTED CLINICIAN REMARKS)

Instructions to clinicians: At this point show sections 3 and 4 of the video. There should be less discussion of these sections since you have covered this material in your presentation.

D. Diagnosis and Symptoms

A. The *Diagnostic and Statistical Manual* of the American Psychiatric Association.

Families benefit from knowing how we make diagnoses and knowing the criteria for the diagnosis. Clinicians can help families by introducing them to the *DSM* in these ways:

1. Show participants a copy of the manual and let them pass it around and look at it. This helps family members appreciate the number, type, and complexity of diagnosis.
2. Reproduce the diagnostic criteria for the mental illness about which you are teaching and explain what each one means. Give definitions and examples of psychotic symptoms, mood symptoms, and decline in social, vocational, or interpersonal skills.
3. Explain the reasons for uncertainty in diagnosis and why a mentally ill relatives' diagnosis may change.
4. Connect the symptoms to brain dysfunction.
5. Explain positive and negative symptoms. Many people find it hard to accept that mental illness has an effect on motivation, hygiene, and speech. You will need to explain negative symptoms several times.
6. Explain the difference between Axis One disorders and Personality Disorders.

B. An Extended Discussion of Symptoms

(SUGGESTED CLINICIAN REMARKS)

The *DSM* does not describe every mental phenomenon considered a symptom. Here is a presentation of symptoms based on E. Fuller Torrey's *Surviving*

Schizophrenia. Your folder contains a list of these symptoms. I will describe each one for you.

1. Alterations of senses and attentional capacity:

- Over-sensitivity of senses, e.g. normal speech sounds like screaming.
- Under-sensitivity to sensations like pain or coldness.
- The mind is flooded with thoughts or memories.
- Distractability.
- Inability to attend to stimuli.
- Decreased ability to attend to tasks, conversations, or events for extended periods of time.

2. Misinterpretation of incoming sensations, leading to inappropriate responses:

- Difficulty concentrating.
- Loose associations, i.e., speech will display disconnected thoughts or bizarrely connected thoughts.
- Misinterpretation of visual or auditory cues.
- Inappropriate emotional responses, e.g., laughing when there is nothing funny in the surrounding environment.
- Decreased ability to think abstractly.
- Neologisms, making up new words.
- Word salad, stringing together series of disconnected words.
- Blocked thoughts, the person will want to express some thoughts but they are stuck and unable to express them

3. Hallucinations and Delusions

Hallucinations are sensory experiences that lack corresponding environmental stimulus. Hallucinations can be present in any of the five senses:

- visual, seeing things;

- auditory, hearing voices;
- olfactory, offensive smells coming from one's body or food;
- tactile, feeling unpleasant sensations on one's skin;
- gustatory, offensive tastes associated with foods.

Delusions are false beliefs that are resistant to evidence that would make an ordinary person give up those beliefs, and that are not consistent with the patient's culture. There are many types of delusions:

- paranoid, beliefs that someone is watching the patient, persecuting them, arranging events so their life goes badly.
- grandiose beliefs that one is wealthy, famous, or has a unique power.
- religious delusions of a mission or message from God.
- somatic delusions, beliefs that one has an illness.
- guilty delusions, beliefs that one is responsible for a catastrophe, an illness, or evil for which one has no responsibility.
- nihilistic delusions , e.g., beliefs that one doesn't exist, that one cannot die, or that one has died and been replaced by somebody else.
- delusions of reference, irrational beliefs that events relate directly to you, in either a threatening way or indicating some special mission you have.

4. Misinterpreting one's own thoughts.

- Feeling like one's mind is controlled by an outside force, agency, or other person.
- Thought insertion, experiencing one's thoughts as if they are inserted by someone else.
- Alienated thoughts, experiencing one's thoughts as if they belong to someone else.
- Thought withdrawal, experiencing one's thoughts as if they are being taken from one's mind.

- **Thought broadcasting, experiencing one's thoughts as if they are going from one's mind to a television, radio, or internet broadcast.**

5. An altered sense of self.

- **Experiences of dissociation or detachment from one's body or specific body parts.**
- **Experiencing one's self as unreal or disconnected from past experiences.**
- **Lack of memory or things one said or did during a psychotic episode, resulting in gaps in one's remembered sense of self.**

6. Inappropriate or unusual emotions.

- **Exaggerated feelings, especially fear, guilt or anxiety that may be related to delusional beliefs.**
- **Rapid changes of emotion.**
- **Dulled emotional responsiveness.**
- **Inappropriate emotional responses, which the person cannot explain.**

7. Changes in bodily movements.

- **Awkwardness or clumsiness.**
- **Decreased spontaneity.**
- **Repetitious or ritualistic movements.**
- **Catatonia.**

8. Behavioral changes

- **As a result of delusional beliefs or hallucinations, a person with schizophrenia may behave inappropriately, threateningly, or dangerously.**

- **A person with schizophrenia may do socially inappropriate things that are simply unexplainable, walking naked in public or wandering from place to place with no purpose.**
- **Mimicking what other do or repeating what others say.**

(END OF SUGGESTED CLINICIAN REMARKS)

C. Positive and Negative Symptoms

The distinction between positive and negative symptoms is subtle and unfamiliar to many family members. Negative symptoms are not treated as well as positive symptoms, and present family members with one of the most frustrating aspects of illness management. Here are some basic things you may want to tell families about positive and negative symptoms.

SUGGESTED CLINICIAN REMARKS

- **Positive symptoms are experiences that added to the patient's experiences in addition to normal experiences. Hallucinations and delusions are prime examples of ways schizophrenia adds abnormal things to experiences.**
- **Negative symptoms are experiences, skills, and abilities that are normally present but are absent in a person with schizophrenia. Common negative symptoms are lack of motivation, decreased attention to personal hygiene or one's living environment, blunted feelings, poverty of thought.**

D. Executive functioning

Schizophrenia affects what psychologists call executive functioning, that is, problem-solving, planning, decision-making, and practical reasoning. This has effects in daily

living: budgeting, purchasing, completing household tasks, and judgment of socially appropriate behavior and speech.

E. The purpose of diagnosis

There are several points to make about the purpose of diagnosis.

1. We diagnose an illness not a person.
2. Classification is not the whole of diagnosis but a first step to making a diagnosis. The purpose of classifying an illness is to result in a diagnosis should guide treatment.
3. Family members can ask many questions about the variety and kinds of symptoms. You can remind them that this is the beginning of your work together and you will return to this topic at another time.

Instructions to clinicians: At this time show sections 5 and 6 of "Schizophrenia Explained," following each section by discussion.

E. Course and Outcome

While family members do not cause schizophrenia, they are able to affect the course of schizophrenia. Many people are unfamiliar with the difference between the cause and the course of an illness and need a brief explanation of this distinction. This is a useful time to repeat the messages that family members don't cause mental illness and that recovery is possible.

(SUGGESTED CLINICIAN REMARKS)

Here are the most important things for family members to know about the course and outcome of schizophrenia.

- 1. Recovery is highly variable. This means that there is a wide range of levels of recovery from schizophrenia. Most people with schizophrenia will need**

lifetime treatment, a few will recover completely, and some will need intensive lifetime treatment

2. Recovery is individual. Each individual's recovery should be assessed by the standards of that individual's abilities and goals over time. We use an individual yardstick, measuring how each person does today compared to a month ago or a year ago. There is no standard recovery measure.

3. Families can effect the course and recovery of their loved one with schizophrenia. Establishing a supportive atmosphere, following the family guidelines, collaborating with the treatment team, encouraging compliance with medication and psychosocial treatment are things family members can do to have desired effect on recovery.

4. In your folders is a sheet called "The Psychosocial Typology Of Illness." This diagram portrays the different courses and outcomes of illness. Family involvement in psychoeducation groups and treatment can help turn their loved one from having a relapsing case of schizophrenia to one that has a stable course. Family involvement increases the chances people with mental illness will participate in rehabilitation, so participation makes it more likely your relative will be less severely incapacitated by his/her mental illness.

(END OF SUGGESTED CLINICIAN REMARKS)

F. MEDICATIONS

1. Who should teach families about medications?

Some agencies restrict teaching about medications to medical personnel such as physicians, psychiatrists, and nurse practitioners. We recommend that medical personnel in your agency participate in the Family Education Workshop so that family members get

to know them, ask them questions, and reduce any hesitation about approaching physicians and medical personnel with concerns about medications.

However, medical personnel are sometimes unavailable or only able to attend the FEW for a question and answer period. Any clinician should be able to present basic information about medications used in treating SPMI. Presenting information does not mean you have to become an expert or take over the role of the physician or other prescriber. A presentation of basic information follows. We suggest using it as the basis for your presentation to families, adapting it as your agency needs.

2. Basic Information about Psychiatric Medications

(SUGGESTED CLINICIAN REMARKS)

A. Introduction

Family members sometimes find medications confusing for the following reasons:

- **The number of medications**
- **Professional terminology for medications is unfamiliar to them.**
- **Different names are used for the same medications.**
- **Popular media present conflicting information about medication and its importance to recovery from SPMI.**

The purpose of this talk is to help family members understand what professionals understand about medications.

This talk will cover:

- **Main classes of psychiatric medications**
- **The difference between trade names and generic names**

- **The role of medications in recovery from schizophrenia**
- **How family members can help a mentally ill relative with adherence to his/her medication.**

Different family members have different levels of involvement with their relative's medication. Some know only that their relative is taking psychiatric medication but not which medicine. Others are more involved with observing and getting information to the doctor. Others keep track of medications and prescriptions. Some are involved in actually giving the medications to their loved one as the doctor prescribes.

What kind of involvement family members have depends on you, the recommendation of the treatment team, and the patient's preference.

B. The Main classes of medications

Your folder contains a list of the main classes of medications used to treat schizophrenia, bipolar disorder and other psychotic illnesses. It is helpful to divide psychiatric medications into groups or classes because there are many different medications and pharmaceutical companies are rapidly developing new ones. It is hard to remember the names of many particular medicines but knowing the class of a medication helps you know its purpose. Since classes of medications are defined by their purpose and knowing what class of medication you are hearing about or has been prescribed for your relative will help you quickly associate it with its purpose. The classes are:

Class of medication

- 1. Antipsychotics**
- 2. Mood stabilizers**
- 3. Antidepressants**
- 4. Anti-anxiety agents.**

Target symptoms

- 1. Psychotic symptoms**
- 2. Mood lability**
- 3. Depression**
- 4. Anxiety**

All medications used in psychiatry have unfortunate or unwanted side effects, so we will talk about medications used to treat the side effects of medications. Medications are aimed at "target symptoms" and which target symptoms they are aimed at determine the class of medication.

1. Antipsychotics

- Antipsychotics target the psychotic symptoms of schizophrenia and other mental illnesses: thought disorder, hallucinations and delusions.**
- A misused name is "major tranquilizers." Antipsychotic medications are not tranquilizers, not chemically related to tranquilizers, and though they may have tranquilizing effects, these are side effects, not target symptoms.**
- All antipsychotics effect neurotransmitter function, mostly dopamine but other neurotransmitters as well.**
- Side effects vary according to individual medication and individual taking the medication. Physicians are expected to tell patients about common side effects and monitor patients for whether medications they prescribe cause side effects in patients.**

2. Mood stabilizers

- Mood stabilizers are medications targeted at mood lability. They even out the unstable moods, the highs and lows associated with bipolar disorder.**

- Sometimes mood stabilizers are used to augment or increase the effect of antidepressants.
- Mood stabilizers like Lithium require monitoring of blood levels every 3 months.

3. Antidepressants

Antidepressants are targeted at symptoms of depression. There are several subclasses of antidepressants:

- Tricyclics
- Selective serotonin uptake inhibitors, or SSRI's
- MAOI's

Each subclass of medication is associated with different types of depression and each is associated with different side effects. The SSRI's are the most commonly used antidepressant because they have fewer side effects than the others and are least harmful if the patient overdoses.

MAOI's are usually used as a last resort antidepressant because they interact with many common foods. Patients taking MAOI's are expected to follow dietary restrictions that make them very unpopular. Some of the foods a person taking an MAOI must avoid are: aged cheeses, sausages, vinegar-based marinades. The most popular food excluded: pizza. You can see why MAOI's are usually prescribed only after other antidepressants are found ineffective.

4. Anti-anxiety medications

Anti-anxiety medications, or anxiolytics, are used for reducing anxiety. They reduce anxiety and the "jitters," help people sleep, and are muscle relaxants.

Side effects are sometimes sedation and cloudy memory. These medications can be very helpful but have potential for tolerance and addiction.

C. How Medications are prescribed and changed

Psychiatrists, nurse practitioners, and physician's assistants prescribe medications based on the symptoms of the patient. They find out what symptoms the patient has in three ways:

- **Observation and inference**
- **Patient report**
- **Reports by other professionals, family members, and social network members**

Based on the symptoms the prescriber knows about, they will make an initial diagnosis and prescribe the medication they think is most likely to help the patient get relief from their symptoms. Doctors prescribe based on symptoms, so all the information they can get is helpful for getting the right medicine for your relative.

Most patients with SPMI need more than one psychiatric medication. Since these illnesses affect multiple parts of the brain/mind and result in many different kinds of symptoms, we have to use more than one medication to treat the illness.

There is usually a monitoring period to determine if the medicine works, what the side effects are, and whether or not the patient and significant others believe the medicine is helpful. Sometimes a patient simply is unable to tolerate the way a medicine makes them feel so the doctor may change a medicine to one more tolerable for the individual patient.

A doctor may have to try different doses or different combinations of medicine in order to find the right medicine for your relative. The only way to find the right medicine is to prescribe one and see if it has an effect on the symptoms that bother or distress the patient.

Family members can help in the process of prescribing and changing medications in these ways:

- **Learning about medications and symptoms**
- **Accompanying your loved one to some appointments with the psychiatrist or other prescriber.**
- **Monitoring for changes in symptoms, behavior, or side effects and reporting them to the doctor or other professional.**
- **Helping your loved one take the medication as prescribed.**

If you think there is a problem with your relative's medication it is important to let the psychiatrist, nurse practitioner, therapist or case manager know about the problem.

(END SUGGESTED CLINICIAN REMARKS)

D. Medication Refusal

There is a long history of problems taking medication that clinicians have called 'medication compliance' or 'treatment compliance.' A problem with these concepts is that they imply a command-and-obedience relationship between clinicians and patients.

Terms like 'medication adherence' or 'treatment adherence' imply a partnership rather than commanding relationship.

If clinicians communicate the command-and-obedience view of medication-taking to family members, they will reinforce family members using less effective behaviors like threats, coercion, and instilling fear to motivate patients to take medication. More effective behaviors to motivate taking medication are empathizing with side effects, establishing a collaborative relationship with prescribers, and connecting medication compliance with patients' desires to meet goals for work, school or independent living.

Unfortunately, due to frustration and difficult experiences, clinicians may feel stuck in the command-and-obedience relationship with patients. Clinicians may need to spend time discussing their attitudes toward medication adherence with supervisors or with the Family Services Committee.

(SUGGESTED CLINICIAN REMARKS)

We need to spend some time talking about refusing medication. Medication refusal is very frustrating because we care about people with mental illness and we know that taking medication is the most important factor in reducing suffering, preventing relapse, and helping patients reach their goals.

Medication refusal and treatment refusal are not unique to people with mental illness.

How many people here have not done something recommended by a doctor or health care provider? Raise your hands. Think about recommendations to change your diet, get more exercise, take a particular medication, and reduce stress. [Raise your hand. Most people in the room will raise their hand.]

No one changes behaviors easily. Very few of us incorporate medication or medical treatment into our lives easily.

It is estimated that about 50% of people with schizophrenia stop taking medication by 8 mos. after their first hospitalization. That's about the same percentage of people who stop taking hypertension medications. A much higher percentage of people don't follow recommendations to reduce calories and increase exercise.

There are several common reasons people with mental illness don't take recommended medications.

- **Lack of insight; people don't believe they are ill.**
- **People believe they are cured; they don't believe the illness is chronic.**
- **Side effects; they believe the side effects are worse than active symptoms.**

In your folders is a list of things you can do to help your mentally ill relative take medication and some behaviors to avoid because they aren't very effective at motivating people to take medication.

Let's look at that list together. [Review the list with examples from your practice.]

An important distinction is the difference between *symptoms* and *side effects*.

***Symptoms* are the signs of the illness that medication is intended to treat.**

***Side effects* are unintended effects that often accompany medications. They are individual for each patient and vary in frequency and severity.**

Common side effects are:

- **Tardive Dyskinesia**
- **Weight gain**
- **Parkinsonian effects**
- **Sedation**
- **Decreased libido**

G. PSYCHOSOCIAL TREATMENTS FOR SPMI

The clinician teaching the FEW should list and briefly describe the major psychosocial treatments for severe and persistent mental illness. The point is not to fully describe psychosocial treatments but to give family members a basic idea of the variety and purpose of different psychosocial treatments. Also, the clinician can use this part of the FEW to dispel myths about therapy, such as the belief that psychoanalysis or behavior therapy can "cure" schizophrenia, bipolar disorder, or SPMI. This is a good time to refer participants to the handout "Acronyms, Abbreviations, and Terms" which gives a list they may find helpful.

(SUGGESTED CLINICIAN REMARKS)

There are several basic psychosocial treatments for schizophrenia and mental illness that we have found help family members to know about.

Assertive Community Treatment: Assertive Community Treatment (ACT) is provided teams of mobile clinicians who meet with high-risk consumers in community settings to provide support, skills training, and medication management, in order to keep consumers linked to treatment and avoid re-hospitalization.

Case management: Service provided who by a professional coordinates all aspects of an individual consumer's psychiatric treatment, rehabilitation, and social services. Case management provides assistance with housing, applications for financial support and insurance, advocacy, transportation. Case management comes in different levels depending on the number and severity of needs of the individual consumer.

Continuing Day Treatment: A service in which consumers attend program several days a week, several hours per day. Meals are served, group treatment is conducted, and organized social and recreational activities are available.

Family Consultation: A series of 2-4 meeting between family members and a professional to identify a family's specific concerns, formulate several recommendations for the family members to consider, and assist family members in deciding which recommendation to carry out.

Family Involvement: Family involvement in treatment planning and treatment review increases the effectiveness of all psychosocial treatments.

Psychoeducational Multiple Family Group: A series of meetings with clinicians, family members, and consumers lasting from 9 months to 5 years in which clinicians provide information and guidance as families use a structured problem-solving process to enhance their consumer's recovery and rehabilitation.

Psychiatric Rehabilitation: A structured process by which consumers meet with professionals who help them establish goals and plans for achieving their goals in one of the following areas: living, working, socializing, learning.

Social Skills Training: A structured treatment provided in groups or individuals, with the purpose of helping individual consumers acquire skills needed for successful social life, typically advancing in a series of steps from basic tasks to complex tasks.

Supportive individual therapy: people with SPMI benefit from supportive individual therapy that focuses on practical problems in living and developing skills needed to manage life more effectively.

(END OF SUGGESTED CLINICIAN REMARKS)

Points to emphasize:

- The importance of family collaboration with clinicians and professionals providing psychosocial treatment.
- Recognize past family therapies and treatments that blamed families for causing mental illness.
- Family members can affect the course of mental illness but are not responsible for causing mental illness.
- Confidentiality and the means by which agencies can assist family members even though a consumer may want his/her treatment kept confidential.

H. BIPOLAR DISORDER

1. SOME BASIC FACTS

Bipolar disorder is a mental disorder characterized by severe mood swings between depression and mania.

It affects between .8% and 1.6% of the population.

It affects both genders equally and is more prevalent in people of middle to upper socioeconomic class.

2. DESCRIBING MANIC AND DEPRESSIVE EPISODES

- a. The *Diagnostic and Statistical Manual* of the American Psychiatric Association

It is helpful to photocopy the diagnostic criteria for a manic episode and a depressive episode from the *DSM* and use them to guide your discussion with family members. You should describe each symptom in direct, straightforward terms, and ask family members to describe their experiences with that symptom in their loved one with a mental illness.

Here is a description of mania and depression from Miklowitz & Goldstein, pp. 20-21:

I walked into a real fancy restaurant with my mother and started jumping around and running, and there were these chandeliers on the ceiling. I thought I was Superman or something, and I leapt up to grab onto one of them and started swinging on it . . . [when you're manic] you think you're God . . . and that the world is revolving around you, that you can change nature, and the birds will come to you if you call them.

[When I'm depressed] I feel like there's no hope . . . I feel like suicide is the only solution. There've been days on end where I would just stay in bed . . . I didn't want to talk or spend time with anybody, not even my wife . . . I would call in sick and just stay in bed . . . You just give up like there's no future for you.

Here are important points to mention to family members:

- Normalize the mistakes people may make admiring the energy, ambition, and creativity consumers appear to have during manic episodes.
- Discuss family members' fears for loved ones who do dangerous or reckless things when they are manic.
- Emphasize the difference between normal sadness and depression.
- Discuss suicidality and dangerous behaviors associated with bipolar disorder and depression.

b. STAGES OF BIPOLAR DISORDER (From Miklowitz and Goldstein, *Bipolar Disorder: A Family Based Approach*)

Bipolar disorder often occurs in three progressive stages.

Stage 1	Prodromal Hypomanic period
Stage 2	Manic escalation
Stage 3	Mania accompanied by psychosis

It is important to note the variability of the illness progression in bipolar patients, that some patients may skip some stages and have only brief periods when these stages are identifiable. Depression often follows a manic episode, the exact length of a manic episode is unpredictable, and the phenomenon of rapid cycling between manic and depressive episodes makes the illness frustrating and difficult for family members.

c. TREATMENT OF BIPOLAR DISORDER

There are several very effective medications for bipolar disorder, which, when taken regularly, are able to reduce the number of episodes of depression and mania and make the episodes less traumatic for consumers and family members. The primary medications for bipolar disorder are the mood stabilizers, though consumers may need antipsychotics or antidepressants as well.

Mood Stabilizers

<u>Commercial Name</u>	<u>Generic Name</u>
Lithobid	Lithium
Depakote	Divalproex, divalproic acid
Tegretol	Carbamazepine

d. EFFECTS OF BIPOLAR DISORDER ON FAMILY MEMBERS

1. Coping with Symptoms

It is helpful to discuss the differences between bipolar disorder, depression, and schizophrenia, to help family members appreciate the types of illness. Tailoring advice for symptom management, based on the consumer's illness, is important.

2. Coping with Disability

In bipolar disorder, the range of disability varies more than in schizophrenia. Since people with bipolar disorder sometimes have periods of relatively high functioning, it is sometimes frustrating to family members when they have to cope with the rapid changes in their relative's ability.

f. FAMILY MANAGEMENT OF BIPOLAR DISORDER

Here are the most important things family members can do to help manage bipolar disorder and assist their loved one's recovery.

- Medication adherence.
- Stress Management.
- Clear Communication.
- Problem-solving.
- Participating in treatment planning.

4. THE FAMILY'S ROLE IN RECOVERY FROM MENTAL ILLNESS

A. Family Responses to Mental Illness

During this part of the FEW clinicians should take the opportunity to express empathy with family members' struggles with mental illness, introduce the family guidelines, and discuss the structure of psychoeducational multiple family groups. It gives family members an opportunity to discuss successful coping strategies, to learn how they can help their relative's recovery, and what we have reasons to believe are the most effective means they available to them to help in recovery.

Having a family member diagnosed with a mental illness is traumatic for most people. Clinicians should expect the same variety of responses to diagnosis with a mental illness they would expect to any traumatic event. Family members whose relative was diagnosed long ago may have more fixed responses but they also have the wisdom of experience living with a mental illness for a long time.

Starting with family responses to mental illness is a good opportunity for clinicians to show they are not blaming families but are open to family members' varied experiences while coping with mental illness.

(SUGGESTED CLINICIAN REMARKS)

Families have various responses to finding out a relative has a major mental illness. There are common emotional responses and common behaviors that families use to cope with a relative's mental illness. What are some common emotional responses? [Ask families to suggest some, writing them on a whiteboard, blackboard, or newsprint pad, or typing them on a powerpoint screen. Acknowledge each one.] I have talked with many family members and found these are common emotional responses

- **sadness**
- **grief**

- anger
- confusion
- disbelief, denial
- relief
- guilt, self-blame

These are common emotional responses to finding out a relative has a mental illness. Some indicate the level of blame and guilt we feel. Other indicate the relief we feel at finally having a name for something we couldn't name before.

There are also common behavioral responses we have found in families. [You can go through the same process of soliciting behavioral responses, or simply present these.] Some common behavioral responses are:

- withdrawal
- social isolation
- sleep problems
- tearfulness
- arguments (with your mentally ill relative or others)
- fatigue

You may experience any, all, or some of these emotional or behavioral responses to your relative's mental illness. The behavioral responses are understandable but also lead to isolation of families with mental illness.

I want to mention the causes that help explain these responses and talk about how psychoeducational multifamily group helps. The causes are stress, stigma, and burden.

Stress. Having a relative with mental illness is stressful for family members, and stress makes us more disposed to the emotional & behavioral responses and listed above. There is the stress of coping with a mentally ill person's behaviors, of coping with a strange and sometimes unhelpful mental health system, and the stress of seeing someone you love suffer.

Stigma. Most of us absorb ideas about mental illness from our culture and our culture provides many ideas about mental illness to make family members feel ashamed and blamed. Ideas about bad mothers, family communication, and poor parenting make parents and other relatives feel like they caused mental illness. Even though these ideas aren't true, it is hard to keep them from having an effect on us.

Burden. Family members bear the burden of caring for someone with mental illness. We usually divide this into subjective burden, the emotional and psychological aspect, and objective burden, the tasks that are added to our "to-do lists" if we are family members who have to provide transportation, advocate with systems, give professionals information, check on medication and insurance. All these tasks are part of life with a mentally ill relative.

How does PEMFG help?

Instructions to clinicians: At this time show section 7 of "Schizophrenia Explained," followed by discussion.

PEMFG helps family members by addressing emotional needs, providing social support networks, and teaching a method for solving the problems associated with mental illness.

Emotional needs get addressed by the support family members are able to give each other in PEMFG groups. Family members consistently say that there aren't other places and other people who understand them like other family members do.

Social support networks come with PEMFG groups, so that family members feel less isolated, less alone with their relative.

We teach a structured problem-solving method in PEMFG groups to help family members and consumers accomplish the tasks that are part of recovery from mental illness.

(END OF SUGGESTED CLINICIAN REMARKS)

B. The Family Role in Recovery

After discussing family responses to mental illness and the burden of aiding a mentally ill relative with recovery, you are ready for a transition to parts of the FEW that emphasize PEMFG's help for family members, practical tips, and a hopeful and positive concluding message.

(SUGGESTED CLINICIAN REMARKS)

The next part of our workshop talks about what we offer families in PEMFG to help in living with a mentally ill relative. We show a video by Dr.

McFarlane that describes the multiple family group, we discuss the family guidelines, and describe how the multiple family group works.

Play section 7 of *Schizophrenia Explained*.

C. THE FAMILY GUIDELINES

During the afternoon for the one-day format or during the last meeting of the three-session format, clinicians should present the Family Guidelines. Give each participant a copy of the guidelines so they can refer to them as the clinicians lead a discussion.

Clinicians take turns reading a guideline, connecting it to the biological information previously presented, and asking family members for questions and experiences. You help families by illustrating the guidelines with general examples based on the problems families described during the joining sessions.

Since this is the first time many family members will hear the guidelines explained formally, clinicians should relate them to concrete examples and coping strategies.

Maintain a hopeful tone throughout. Suggest that family members put the guidelines in a prominent place at home and make extra copies available for people to take home. Here is a suggested presentation of the guidelines.

(SUGGESTED CLINICIAN REMARKS)

I want to review the family guidelines with you. These practical tips have helped many families and consumers to manage their mental illness and to make strides toward recovery.

The Family Guidelines

1. GO SLOW. Recovery takes time. Rest is important. Things will get better in their own time.

To tolerate the slow rate of change for many people with mental illness, use an “individual yardstick.” As consumers recover from an acute episode, encourage both family members and consumers to compare current functioning to those of a month ago rather than someone else’s current behavior.

The yardstick concept came from a consumer, a bright young, student who was very frustrated after hospital discharge. Although she did well, she couldn’t keep up with the other people in her class and couldn’t do the same things she used to do with ease. After spending months getting depressed and furious because she didn’t have the ability she once had, she learned on her own how to gauge change. She said, “I have to compare myself to where I was 6 months ago, not to where my brother is today, not to where my peers are today, but to where I was 6 months ago. I have to ask myself ‘Am I better now than I was then?’”

If you can learn to use the individual yardstick to measure success, you can develop a greater tolerance of the slow progress inherent in the recuperative process. The goal is to see and appreciate the “inches” of improvement as they occur, thus decreasing feelings of discouragement and hopelessness

2. KEEP IT COOL. Enthusiasm is normal. Tone it down. Disagreement is normal. Tone it down, too.

Family members need to limit interactions that overstimulate their relative with schizophrenia. We recommend that you modulate the highs and lows of family interaction, to create a family attitude of “benign indifference.” Encourage them to minimize both the negatives of nagging, rejection, fights, and conflicts and the positives of extreme concern, encouragement, and enthusiasm.

An example of how both extremes are upsetting was provided by a consumer. He described his upset when his mother would continually nag him to take out the garbage. He described at least as much upset when she stopped berating him and rewarded him excessively (“That was wonderful”) when he did carry it out. As he stated, “I knew it was no big deal to carry out the garbage. I just knew how much I had been letting her down when she made such a big deal over nothing.” This example underscores the importance of benign, neutral responses, however difficult they may be. The idea is to create distance without rejecting the patient.

3. GIVE EACH OTHER SPACE. Time out is important for everyone. It’s okay to reach out. It’s okay to say “no.”

Allow consumers to withdraw when they seem to need to do so, and learn to recognize the individual behaviors that signal the need for “time out” from interaction or activity. This may mean simply allowing patients to keep the doors to

their rooms closed, to have a room in a quiet part of the house, to eat dinner away from the rest of the family, to know in advance when company is coming, and so on. To help avoid complete withdrawal of patients during the phase of recovery from an acute episode, offer consumers opportunities to engage in activities but to accept patient refusals if they seem unable to participate or need to be by themselves.

4. SET LIMITS. Everyone needs to know what the rules are. A few good rules keep things clear.

Another method of decreasing the likelihood of overstimulation of the patient and overextension of your coping resources is the creation of reasonable rules for living together and the reinforcement of them through setting limits. Don't confuse the need for low stimulation with permissiveness. Just because a family member has a mental illness, you should not do whatever they ask. Creating rules and limits may seem to conflict the attitude of "benign indifference." But clear rules and guidelines develop the structure that makes benign indifference possible.

External limits are reassuring to consumers who feel overwhelmed by the chaos in their own minds, and these limits also are crucial in preparing patients to live in the real world, a world that will be less tolerant of bizarre or symptomatic behaviors. It is also emphasized that limits are important in helping to keep the level of stress placed on other family members within tolerable bounds. It is never helpful to permit patients to engage in unusual rituals or strange, irritating behaviors if they unduly upset others in the family.

5. IGNORE WHAT YOU CAN'T CHANGE. Let some things slide. Don't ignore violence.

Without carefully established priorities, it is extremely difficult to maintain a suitable environment. No one can change everything at once, and attempting to do so makes everyone feel overwhelmed and hopeless.

With your family clinician, you and your mentally ill relative should choose one or two issues focus on initially. After these first issues are managed successfully, you can decide what issues to tackle next. Ignoring negative behaviors is always difficult, but most families we have worked with are and willing to do so if they have established their own priorities, if they can see progress in other areas, and if they can believe that the other issues will be addressed eventually.

However, never ignore violent, threatening, or psychotic behavior. The incidence of violence among schizophrenic patients is small, much smaller than media reports would have you believe. The majority of people with schizophrenia are remarkably unassertive. As a clinician I am more frustrated by unassertiveness and passivity than I am frightened by the threat of violence.

However, in the event that of violence or threats of violence, here are some suggestions. First, because violent acts may be precipitated by delusional thinking or hallucinations, rational discussion rarely is effective in toning things down.

Rather, a good deal of violence can be avoided by establishing and maintaining a structured environment and agreeing in advance on the limit-setting procedures already described. Patients who are not overwhelmed by stimulation are less likely to react catastrophically.

If you have experienced violence from your relative with a mental illness, your clinician should review the warning signs of violence and help you develop a response plan. Warning signs and precipitants of violence are very individual, so it is important to be very specific in reviewing these events.

6. KEEP IT SIMPLE. Say what you have to say clearly, calmly, and positively.

In your multiple family groups, the clinicians will work with you on maintaining simple, specific communications with your relative with a mental illness. We recommend communication that is simple with the amount of detail your relative can absorb. We emphasize three communication skills.

1. The ability to acknowledge the statements of others and to accept responsibility for one's own communications. In any family, a certain amount of "mindreading" occurs. That is, family members make the assumption that someone else's thoughts are known even if they are not expressed. These assumptions can cause particular difficulties and create distorted communications. Thus, family members, and eventually patients, are not only encouraged to speak for themselves, but also to avoid assuming they know what others want or need, and to accept and respect what others say even if they don't agree with it.

2. With patients who have difficulty processing incoming stimuli, pauses and delays in communication responses are common. Naturally, family members sometimes develop the habit of speaking for the patient. The unfortunate result is that patients become less and less responsible for their own messages and have less sense of being separate, autonomous adults. Thus, it is important to help family members learn to wait and to respect the patient's ability to contribute to the conversation.

3. Keep things at a moderate level of specificity, avoiding excessive detail or too many abstractions. When families are experiencing times of crisis, it is not appropriate to discuss highly charged issues that are rarely resolved under the best of circumstances. The meaning of life, sexuality, religion, or politics are issues that tend to be highly emotional even when things are going well. Avoid topics such as these while the consumers are floridly ill.

7. FOLLOW DOCTOR'S ORDERS. Take medications as prescribed. Take only medications that are prescribed.

Medication is one way to decrease the patient's vulnerability to stress and stimulation. Most people are ambivalent about taking medication. Earlier in the workshop we reviewed helpful ways of responding to your relative's refusal to take medication.

8. CARRY ON BUSINESS AS USUAL. Re-establish family routines as quickly as possible. Stay in touch with family and friends.

Family members need to normalize their own routine as much as possible because you are involved in a demanding task long-term care. During the acute phase of mental illness, it is necessary for the rest of the family to focus their attentions and their energies on the consumer. However, in any long-term illness (like diabetes, heart disease, or schizophrenia), consumers must learn to live with their limitations and people around them will go on with their lives. If you do not restore your own life, the impact of illness can be harmful to family and marital life. Good parenting begins by the parent taking care of him or herself. This is also true in marriages: Being a good spouse begins by taking care of your own needs. If you are overwhelmed, you will not be helpful to your relative's recovery. Even if self-care is difficult, it is vital for preserving everyone's emotional and physical health. Furthermore, if family members are negatively affected by the consumer's illness, the consumer patients may start to feel guilty and responsible, experiencing their family as a burden, not a support.

9. NO STREET DRUGS OR ALCOHOL. They make symptoms worse, can cause relapse, and prevent recovery.

There are things we consume to feel good that are not helpful to people trying to recover from a mental illness. Caffeine intake, particularly in the form of colas and coffee should be limited. Alcohol consumption should likewise be limited. Requiring complete abstinence sometimes creates more problems than it solves. Your mentally ill relative's clinician should discuss with you the pros and cons of alcohol use and whether your relative has a diagnosis of substance abuse. If your relative has a substance abuse diagnosis, specialized dual diagnosis treatment may be recommended.

However, because alcohol use frequently potentiates or enhances the effects of psychotropic medication, we strongly recommend that consumers do not drink alcohol. Further, alcohol is a central nervous system depressant, even in moderate doses, and might exacerbate the depression that is frequently observed during the recovery phase of schizophrenia. Illegal drug use is an overwhelming obstacle to maintaining consumers at work or in vocational rehabilitation programs. All illegal drugs should be avoided. If your mentally ill relative uses illegal drugs or you suspect they use illegal drugs, you should talk with their clinician and psychiatrist about your concerns.

10. PICK UP ON EARLY WARNING SIGNS. Note changes. Consult with your family.

In multiple family groups we will help you develop a list of early warning signs that indicate your relative may be having a relapse. Not every symptom means that a consumer is having a relapse but it is important to be aware of which signs are

relevant to your relative. If you ignore warning signs to keep the peace, you will not help your relative avoid potential relapses and reduce his/her chances for recovery and rehabilitation.

11. SOLVE PROBLEMS STEP-BY-STEP. Make changes gradually. Work on things one at a time.

12. LOWER EXPECTATIONS, TEMPORARILY. Use a personal yardstick. Compare this month to last month instead of last year or next year.

After an acute psychotic episode, consumers often need an extended period of recovery in which they cannot function as well as they did before the acute episode. If this is your relative's first episode, the hospitalization may have been brief, this does not mean that the illness is not serious and that recovery will take a long time. After the initial stabilization of psychotic symptoms, a period of inactivity, a motivation, and excessive sleep is common. Even if patients do not experience these negative symptoms, they tend to have restless energy, with little ability to follow through effectively on even small tasks. Thus, the need for increased rest, sleep, withdrawal, and limited activity for a period of time is predicted in advance. These patterns are the natural course of the illness and not signs that your relative is lazy. Inactivity and amotivation are another stage of the illness. So, we recommend lowering expectations after an acute psychotic episode to accommodate this natural healing process.

Chapter 5: Discussion Guide for *Schizophrenia Explained*

Please consider the use of this discussion guide as a companion to the videotape, *Schizophrenia Explained*. You may stop the tape at various intervals in order to have a dialogue with your audience and to highlight important points in the video. Feel free to pose questions to your audience to help insure they understand the material presented. The content in this film is broken into 7 sections. There are no cues on the video, but Dr. McFarlane does announce when he is moving into the next topic area. These sections include:

- | | |
|---|-------------|
| 1. How We Have Come to Understand This Disease. | Pages 44-45 |
| 2. Its' Prevalence in Society. | Page 45-46 |
| 3. The Inner Experience. | Pages 46-48 |
| 4. The Public Perspective. | Pages 48 |
| 5. The Role of Brain Functioning in Schizophrenia. | Pages 49-50 |
| 6. Possible Causes of Schizophrenia. | Pages 51-52 |
| 7. The interaction between medication and the psychological and social environment. | Pages 52-54 |

Section 1: How We Have Come to Understand This Disease

This section gives a historical perspective on schizophrenia, from the Middle Ages when people thought schizophrenia meant the sufferer was possessed by the witches or the devil.

It then describes the 4 basic characteristics of schizophrenia:

1. Ambivalence
2. Autism
3. Loose associations
4. Loss of affect

From the early to mid-20th Century Freud and others believed that childhood trauma caused mental illness, therefore treatments focused on **healing** the hypothesized underlying trauma. This hypothesis did not lead to effective treatment and is not widely held today. We now see schizophrenia as a disease of the brain, not a mental weakness,

not a fault of the family, but rather a brain disease like other medical and neurological illnesses.

The illness is treatable though not curable. Effective treatments include:

- Modern medications
- Supportive therapy
- Family support methods
- Rehabilitation methods

Modern Rehabilitation techniques now make it possible for people with schizophrenia to:

- Return to work
- Find a job, sometimes even when one never held a job before the onset of the illness.

These treatments are proven to be effective in:

- Decreasing symptoms
- Preventing relapse
- Improving quality of life (or final outcomes)

There is more hope for people with schizophrenia than ever before. With modern medicine and continued research, the prognosis will most likely improve steadily for the next few years.

Possible Discussion Questions:

1. Why did people once believe the devil or spirits were affecting their family member with schizophrenia?
2. How has treatment changed in the past century? Decade?
3. How can one's family member be seen as an ally in treatment?
4. Why is the future more hopeful for people with schizophrenia?

Section 2: The Prevalence of Schizophrenia

- How common is schizophrenia?
 - 1 out of 100 people have schizophrenia.
- Until the arrival of new medications:
 - ½ of all hospital beds occupied with people diagnosed with schizophrenia
- 1/10,000 people come down with schizophrenia

- 750,000 people treated every year for schizophrenia
- Several million people in USA currently have had or still have
- schizophrenia

Lifetime risk for schizophrenia is the same as for diabetes. In the public domain, one hears a lot more about diabetes. There has been more research and treatment efforts for diabetes than for schizophrenia.

Peak age of onset:

- Men-late teens, early 20's
- Women-middle 20's, early 30's

Possible Discussion Questions:

1. In the past, why were ½ of the hospital beds likely to be occupied by a person with schizophrenia?
2. Why do you think diabetes gets more positive attention in the media and more research funding?

Section 3: The Inner Experience

How the illness begins:

- Early Signs
 1. Mind begins to play tricks
 - Trouble screening
 - Attention disrupted
 2. Ability to generalize
 3. It becomes harder to distinguish the relevant from the relevant information in one's environment.

Information going into the brain becomes overloaded

- Thoughts become fragmented or disjointed
- The ability to apply past experiences as a guide is interrupted
- Personal and internal memories get misapplied in day to day interactions
- A perception of what is actually occurring external to oneself interferes with internal mental processes.

As the illness progresses:

- Extraneous thoughts and noises become equivalent to the thoughts the person is having. The two begin to get jumbled.
- The person has difficulty coming to correct conclusions
- Sense of being overloaded
- Person cannot filter things out
- Person feels constantly bombarded

Simulated Auditory Hallucinations

- Demonstration of hallucinations one might experience when their sense of hearing becomes affected.
 - Normally we'd glean important aspects of conversations, but with distractions coming at you, it becomes more difficult.
 - As one is trying to screen out the sounds s/he is hearing, in order to focus on what is relevant, it becomes more and more difficult.
- The simulation demonstrates heightening of sensation:
 - Total amount of sensations, or experiences, is much larger than what is actually occurring because the person cannot filter out the irrelevant.
 - It becomes more difficult to relate to others.
 - Sensory process becomes more global.
 - Sensations become altered and more intense than they actual are.
- As the symptoms continue, the person frequently withdraws and avoids others.
- As the person's state of arousal increases, s/he experiences:
 - Higher states of anxiety
 - Increased distractibility
 - Increased difficulty functioning

Possible Discussion Questions:

1. Are the simulated auditory hallucinations a good example of what hallucinations actually look like to someone who has schizophrenia?

2. How might a person with an alteration in their perceptions appear to other's who do not have the same perceptions?
3. Why do people with schizophrenia sometimes appear suspicious or fearful?

Section 4: The Public Perspective

- Thought disorder
 - Delusions
 - Thought broadcasting
 - Fixed beliefs, resistant to change based on new information
 - Suspiciousness
 - Auditory hallucinations
- Positive symptoms: experiences that are added
- Negative symptoms: experiences that are taken away
 - Alogia-Loss of speech
 - Affective flattening-Loss of emotion
 - Avolition-Loss of motivation
 - Anhedonia-Loss of pleasure
- Less spontaneous
- Depression may occur in response to symptoms
- Sensitive to perceived criticism
- Decrease in social skills

Possible Discussion Questions:

1. What is meant by positive symptoms in schizophrenia?
2. What is meant by negative symptoms in schizophrenia?
3. How could social skills rehabilitation benefit a person with schizophrenia?
4. What are some ways in which people in the general public would view, or judge, a person who appears confused, slowed down, and sensitive to criticism?
5. What are 2 things family members could do to support their relative who is experiencing positive or negative symptoms of schizophrenia?

Section 5: The Role of Brain Functioning in Schizophrenia

Attention/Arousal Theory

- People with schizophrenia have great difficulty attending when over-aroused or over-stimulated
- If arousal, or stimulation, is kept at a minimum, then the person with schizophrenia is able to maintain their attention.
- As arousal increases, the person with schizophrenia experiences:
 - Higher states of anxiety
 - Increased distractibility
 - Increased difficulty functioning
- Person with schizophrenia needs:
 - Calm environment
 - Simple environment
 - Fewer stresses
 - Fewer changes
- The Family Guidelines help you establish and maintain a calm environment and structure behavior in ways that are most helpful to your relative with schizophrenia.

Side View of the Brain-Over 100 billion cells in the brain. It is the most complicated structure of the human body.

- Brain Stem and Mid-Brain-Regulates activation of neurotransmitters
 - Dopamine
 - Serotonin
 - Noradrenalin
 - Glutamine
- Pre-Frontal Cortex-Area responsible for higher mental functioning. In folks with schizophrenia, this region is reduced by about 1/2.
- Temporal Lobe-Area responsible for ability to understand language, speech and hearing.

- Occipital Lobe-Area responsible for processing visual input.
- Limbic System-Area responsible for integrating thoughts and feelings.
 - Hippocampus-Area responsible for short-term memory and attention. High level of disorganization at this level in folks with schizophrenia.
 - Difficulties at the hippocampus level
 - Thought disorder in attention
 - Trouble avoiding distracting stimuli
 - Short-term memory problems
 - Thalamus-Area responsible for regulating sensory input. This area is smaller in folks with schizophrenia; therefore, they may experience excessive sensory information.
- Synapse-Point of contact between 2 cells.
 - Reviews process of neurotransmitters being released in the synaptic gap and visually describes how people with schizophrenia have an over-stimulation of neurotransmitters being released.

How the medications work

- Most of the medicines work by occupying sites on the receptors.
- Dopamine gets blocked, and in turn the person is able to process, or understand better.
- Most medications help to limit over-arousal.

Possible Discussion Questions:

1. How does the medicine help someone with schizophrenia?
2. If our family only changed the environment would our relative recover from schizophrenia?
3. How do clinicians know if someone is clinically depressed or if they having negative symptoms of schizophrenia?
4. How are negative symptoms managed by the treatment team?
5. How are positive symptoms managed by the treatment team?

Section 6: Possible Causes of Schizophrenia

- The best-supported causes are biological.
- Do not involve family pathology or the individual being at fault
- Genetics
 - 10% chance of children developing schizophrenia if one parent has schizophrenia
 - 90% of people with schizophrenia do not have a family history of schizophrenia
 - If one identical twin has schizophrenia, there is a 40% chance the other twin has schizophrenia
 - Many people with schizophrenia have no genetic link
- Pre-Natal Factors-A variety of factors during pregnancy may adversely affect the early development of the pre-frontal cortex.
 - Influenza
 - Rh Factor
 - Malnutrition
 - Auto immune disorder
- These could cause neurophysiological deficits that do not show themselves until their full functioning is called upon, in early adulthood. At that time, the inability to handle increased arousal from the demands of independent living may trigger the onset of schizophrenia.
- Some situations in pregnancy may negatively impact the early development of the brain
- Anything that could lead to minor brain damage, or injury, may predispose people to schizophrenia
 - Forceps delivery
 - Oxygen deprivation
 - Spinal anesthesia
- Enlarged ventricles on CAT scans suggest loss of brain tissue or a failure of the brain to develop completely
- Similar to other neurological illnesses
 - As research continues, more evidence of the causes may be found

- Better evidence about causes should contribute to more effective treatment

Possible Discussion Questions:

1. How is the brain of a person with schizophrenia different from the brain of someone without the illness?
2. How is the research about other neurological illnesses useful to scientists researching schizophrenia?

Section 7: The Interaction Between Medication and the Psychological and Social Environment

- The environment has extensive influence on symptoms of schizophrenia
 - Medications are helpful
 - Changes in the environment are helpful
- Extreme stress is difficult for everyone
 - People with schizophrenia often develop psychotic symptoms when undergoing stress
 - With pressures of independence, folks with schizophrenia find they don't have the mental ability required to function
- Life events often precipitate 1st episode of the illness (college, Army, marriage, child birth)
- There is a constant interplay between brain functioning, the outside environment and the person.
- Low doses of antipsychotics over long term:
 - Tend to reduce sensitivity to arousal
 - Improve attention
 - Help build a basis for independent functioning
 - Improve thinking
 - Prevent relapse

- Relapse rates
 - Not on med's-70% relapse rate in first year
 - Taking med's-35% relapse rate in first year
- There needs to be a balance between enough medication to control symptoms with fewest possible side effects.
- Diet/Vitamins/Natural Healing
 - No evidence thus far, proving these are effective means to reign in the symptoms and prevent relapse
- Street Drugs-Universally destructive of the brain and recovery process
 - Cocaine-releases massive doses of dopamine, which is detrimental to someone who already has an overproduction of dopamine because it increases the arousal state
 - Stimulants, such as caffeine and nicotine-also increase the arousal states
 - Alcohol/Marijuana-Depresses brain briefly. Brain interprets these as poisons and provokes activation over long time.
- The medication and social aspects of treatment are both important
 - Medication is crucial in preventing relapse and to return to normal functioning.
 - Medications and family support work together to ensure:
 - Smooth recovery
 - Protection to prevent relapse
 - Reducing stimuli to foster a calm environment
 - As stress level is decreased, it allows the person to withstand more stress in the community (i.e. work)
 - Family support program for 1-2 years after last episode
 - Graph depicts relapse rates
 - 70% relapsed-no med's 1st yr.
 - 35%-40% relapsed-took med's, no family involvement
 - 15% relapsed-took med's, family involvement and changes in environment

- 9% relapsed-took med's, multifamily group involvement, counseling
- Slow, steady, careful approach

Possible Discussion Questions:

1. What effect does stress have on a person with schizophrenia?
2. What can be done to minimize stress for a person with schizophrenia?
3. Why are street drugs poisonous to the brain of a person with schizophrenia?
4. Is it possible to have a good quality of life while having schizophrenia?
5. How can my involvement in a Family Group help improve the outcome of my illness?

Chapter 6. HANDOUTS FOR FAMILY MEMBERS

1. The Family Guidelines
2. Family Education Workshop Schedule
3. The Experience of Schizophrenia
4. Signs and Symptoms of Schizophrenia
5. Classes of Medications
6. Medication Refusal
7. Acronyms, Abbreviations, and Terms

THE FAMILY GUIDELINES

1. **GO SLOW.** Recovery takes time. Rest is important. Things will get better in their own time.
2. **KEEP IT COOL.** Enthusiasm is normal. Tone it down. Disagreement is normal. Tone it down, too.
3. **GIVE EACH OTHER SPACE.** Time out is important for everyone. It's okay to reach out. It's okay to say "no."
4. **SET LIMITS.** Everyone needs to know what the rules are. A few good rules keep things clear.
5. **IGNORE WHAT YOU CAN'T CHANGE.** Let some things slide. Don't ignore violence.
6. **KEEP IT SIMPLE.** Say what you have to say clearly, calmly, and positively.
7. **FOLLOW DOCTOR'S ORDERS.** Take medications as prescribed. Take only medications that are prescribed.
8. **CARRY ON BUSINESS AS USUAL.** Re-establish family routines as quickly as possible. Stay in touch with family and friends.
9. **NO STREET DRUGS OR ALCOHOL.** They make symptoms worse, can cause relapse, and prevent recovery.
10. **PICK UP ON EARLY WARNING SIGNS.** Note changes. Consult with your family.
11. **SOLVE PROBLEMS STEP-BY-STEP.** Make changes gradually. Work on things one at a time.
12. **LOWER EXPECTATIONS, TEMPORARILY.** Use a personal yardstick. Compare this month to last month instead of last year or next year.

Family Education Workshop

- 9:00-9:15: Coffee and socialization
- 9:15-9:30: Formal introductions and schedule of the day
- 9:30-10:30: The phenomenology of the illness
Etiology, course, and outcome of the illness
The private experience of schizophrenia
The public experience of schizophrenia
Diagnosis of mental illness
- 10:30-10:45: Coffee break
- 10:45-12:00: Treatment of Schizophrenia
Medication
How it works
Why it is needed
Impact on outcomes
Side Effects
Psychosocial Treatments
Family Psychoeducation & Family Groups
Social Skills Training
Day Treatment
Vocational Rehabilitation
Psychotherapies
- 12:00-1:00: Lunch
- 1:00-3:30: The family and mental illness
Needs of the patient
Needs of family members
Family members reactions to serious mental illness
Emotional reactions
Common interactions
Common problems that families and patients face
What families can do to help
The Family Guidelines
The problem-solving process
- 3:30-4:00: Questions about specific problems
Description of the MFG process
Keeping hope alive
Wrap-up, scheduling

THE EXPERIENCE OF SCHIZOPHRENIA

Personal Experience

Distraction

"Overload"

Sensitivity

Misperceptions

Public Manifestation

Thought disorder

Delusions

Hallucinations

Social withdrawal and apathy

SIGNS AND SYMPTOMS OF SCHIZOPHRENIA

Alteration of sensation and attentional capacity.

Misinterpreting incoming sensations and misresponding to them, leading to inappropriate responses.

Hallucinations

Delusions

Misinterpreting one's own thoughts

Altered sense of self

Inappropriate or unusual emotions.

Changed bodily movements.

Behavioral changes.

FOUR MAIN CLASSES OF PSYCHIATRIC MEDICATIONS

Class of medication

Target symptoms

1. Antipsychotics

1. Psychotic symptoms

2. Mood stabilizers

2. Mood lability

3. Antidepressants

3. Depression

4. Anti-anxiety agents.

4. Anxiety

MEDICATION REFUSAL

HELPFUL BEHAVIORS

Find a prescriber who communicates well with family members.

Make sure everyone in the family agrees with the medication recommendation. If someone doesn't agree, ask your clinician for a meeting to discuss medication.

Encourage your relative's prescriber to be open about side effects.

Focus on immediate benefits of medication taking: sleep, reduced anxiety.

Talk about the benefits of medication in a factual, nonjudgmental way.

Connect medication taking with goals like work school, or increased independence (e.g., access to a car, decreased supervision, independent residence).

If you assist your relative with medication taking, keep it regular, associate it with other activities, and do it nonjudgmentally.

Encourage your relative to avoid alcohol and street drugs.

WHAT DOES NOT HELP

Complaining about side effects to your mentally ill relative. If you have concerns about side effects, call your clinician or prescriber.

Threats, scare tactics, scolding and punishing.

If you try to assist your relative with medication taking, but find it stressful or that it makes you angry and irritable, consult your family clinician to develop another plan.

	ACRONYMS, ABBREVIATIONS and TERMS
ACT	Assertive Community Treatment
Administrative Champion	Administrator who advocates for family programs to obtain needed resources to develop and maintain family programs
BPD	Borderline Personality Disorder
Champion	Line Staff who advocates for family programs and can instill enthusiasm among other staff
CDT	Continuing Day Treatment
CMHC	Community Mental Health Center
CMI	Chronic Mental Illness
DDSO	Developmental Disability Service Office
Discipline Head	An administrator who is responsible for the activities of staff belonging to a particular discipline or profession, e.g., social work, nursing, psychology, rehabilitation or medicine
DMH	Department of Mental Hygiene
DSM	Diagnostic and Statistical Manual of Mental Disorders; comes in volumes III, IV-R
EBP	Evidence Based Practice
Family Advocacy Group	A group of family members organized independently of an agency that advocates for agencies and officials to provide resources and programs to meet needs of families and consumers
FEW	Family Education Workshop
FIEPR	Family Institute
FSC	Family Services Committee or Family Services Coordinator – agency staff member who coordinates development of family programs
FT	Family Therapy

IST	Interactive Staff Training or Interactive Staff Trainer
IPRT	Intensive Psychiatric Rehabilitation Treatment
MICA	Mentally Ill Chemically Abusing
MFG	Multiple family group
N	Number of subjects or participants
NAMI	National Alliance for the Mentally Ill
NARSAD	National Association for the Research in Schizophrenia and Affective Disorders
NIMH	National Institute of Mental Health
NYSOMH	New York State Office of Mental Health
OCD	Obsessive Compulsive Disorder
PEMFG	Psychoeducational multiple family group
PSYCHO-EDUCATION	A structured process of providing support, information, and skills training in recovery from mental illness for consumers and family members
PSYCH REHAB	Specific set of treatment for SPMI on social and coping skills training and increased role functioning
PTSD	Post-Traumatic Stress Disorder
QA	Quality Assurance
SFPE	Single Family Psychoeducation
SPMI	Serious and Persistent Mental Illness: a term used by NYSOMH. Whether an individual is “SPMI” or not depends on how much mental illness impairs their functioning. This term is important because many programs determine eligibility based on whether or not the person is “SPMI”.
STEMMS	Support Together for Emotional and Mental Sobriety
TRAINER	An outside consultant who joins with agency staff to develop family programs
UR	University of Rochester
VESID	Vocational and Educational Services for Individuals with Disabilities

