

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.