DEPARTMENT OF VETERANS AFFAIRS

Support And Family Education



Session Thirteen – What To Do When Help is Turned Away

Materials Needed:

Handout X: What To Do When Help Is Turned Away

- I. What you can do when your loved one turns away help
 - A. Consumers can reject help in two primary ways:
 - 1. They can reject families' offers of help directly by
 - a. Ignoring you when you offer assistance.
 - b. Becoming angry in an effort to distance themselves from help.
 - 2. They can reject treatment by
 - a. Refusing to take prescribed medications (not taking the medications as the doctor prescribed or not taking them at all).
 - b. Refusing to participate in treatment/therapies/classes.
 - c. Drinking alcohol or using illicit drugs so that prescribed treatments are ineffective.
 - B. Family members often experience the refusal of treatment as very frustrating. They may take the choice personally, even if the decision has nothing to do with them.
 - C. Failure to obtain adequate mental health care is actually quite common. Only about half of all Americans with a serious mental illness seek treatment (Kessler et al., 2001)
 - D. Research has found that depressed people reject support more often than do non-depressed people. Depressed people also ask for help more indirectly (e.g., sulking, picking fights, distancing emotionally or physically) than do non-depressed people (Rosen & Amador, 1996).

II. Why consumers sometimes reject help or discontinue treatment (parts adapted from Adamec, 1996; Rosen & Amador, 1996; Torrey, 1988)

In some ways, the issues surrounding rejecting help and advice are not unique to people with a mental illness. People commonly fail to comply with doctors' orders, even when they know that the directives are good for them. For example, the media and healthcare professionals repeatedly remind us to exercise regularly, decrease our intake of fats, limit our use of alcohol, eat more fruits and vegetables (etc.). Diabetics are urged to modify their diets and monitor their glucose levels. Even with the knowledge of what is "good for us," we commonly make unhealthy choices that can have long-lasting negative effects on our well-being. As the popular adage states, "Common sense isn't always common practice."

In addition, some factors pertain more specifically to mental illness.



<u>Discussion Question:</u> What are some reasons that your loved ones have refused help (either in the past or currently)?

A. Denial

Accepting help actually involves three steps (each of which is significant):

- 1. Admitting to yourself that you have a problem.
- 2. Admitting that you cannot deal with the problem on your own.
- 3. Developing the courage to share your problems with someone else.

Consumers may know that they have a problem, but their pride and need to be independent may prevent them from accepting help. Asking for help can make people feel vulnerable, "weak," (e.g., not "man enough" to deal with it on their own) and ashamed.

B. Pessimism

People who are depressed often describe a negative or pessimistic view of the self, the world, and the future (Beck, 1967). Therefore, consumers may experience outside help as intrusive and useless. Because of cognitive distortions commonly associated with the mental illness and/or bad experiences with previous treatment, consumers may feel hopeless that anything will help.

C. Impaired insight

Some people living with mental illness genuinely believe that they do not need any help. Insight and judgment are commonly compromised with thought disorders, so these individuals may not believe that anything is wrong. They may discontinue their psychiatric medications because they feel better (and think they do not need the drugs anymore), failing to realize that the medications are managing some of the symptoms.

D. "Forgetting" to take the medications as prescribed

The medication regimen that the doctors prescribe can be quite complicated, and consumers may feel overwhelmed with the confusing schedule. They may also be forgetful, so compliance with the daily routine can be difficult (weekly pill boxes can be helpful with this issue). Families are encouraged to consider other possible reasons for "forgetting" if providing structure and support do not improve their loved one's compliance.

E. <u>Discomfort with feeling dependent</u>

Consumers may struggle with allowing someone else to take care of them, especially if they have typically played the role of the caretaker in the family. Accepting help inherently changes the hierarchy and roles in the family, which can result in greater stress.

F. <u>Delusional thinking</u>

Consumers may have paranoid thinking (e.g., believing that medications are poisonous; believing that doctors can read their minds), which can adversely affect treatment compliance.

G. Poor relationships with doctors

Consumers may feel that their doctor/provider does not really care about them and/or does not really listen. Therefore, their trust in the doctor and their commitment to treatment may be damaged.

H. Unpleasant side-effects

Some medications have unpleasant side-effects (e.g., fatigue, weight gain, headaches, stomach upset) that are obstacles to compliance. More specifically, some antipsychotic medications can result in tardive dyskinesia (tremors and other involuntary movements), and some anti-depressants can adversely affect sexual functioning.

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I. Ego-syntonic (pleasant) symptoms

Individuals with bipolar disorder often struggle with medication compliance with the mood stabilizers (e.g., lithium) because manic or hypomanic symptoms (high level of energy, increased productivity, elevated self-esteem, etc.) can be pleasant. In contrast, they may dislike the flattening of affect often associated with these medications so may discontinue the drugs to enjoy the "highs" associated with mania. In addition, some people with schizophrenia find their hallucinations and delusions to be enjoyable and therefore discontinue their antipsychotic medications.

J. Discomfort with loss of control

Some consumers experience taking psychiatric medications as a loss of control over their thinking and behavior. They may fear being "locked up" and being forced into treatments that restrict their freedom. These fears are usually unwarranted, as state laws mandate that consumers are only coerced into treatment if they are an immediate danger to themselves or others.

K. <u>Uncertainty about how to obtain services</u>

Individuals with a mental illness (and family members) often struggle with knowing how to navigate the complex mental health service delivery system. Consumers may not know where to turn and often experience frustration with the overwhelming and fragmented system

L. Stigma

Our society continues to attach a significant stigma to seeking mental health treatment. This barrier can affect an individual's willingness to both seek help initially and comply with ongoing treatment. Families and friends may understand the need for short-term intervention but may become impatient and want their loved one to "get over it" quickly.

M. Finances

Financial issues can be a major barrier to consumers' seeking and staying in mental health treatment. Most insurance plans continue to have considerable disparity in coverage for mental health treatment in comparison with other illnesses. Dealing with restrictions on insurance coverage and inadequate finances can be very stressful for family members. Finances may be less of a deterrent in certain agencies (e.g., VA system).

III. Consequences of having your help turned away

A. When your loved one rejects your help or doesn't participate in his/her treatment plan, you may experience a wide range of emotions.

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Discussion Questions:

- How have you felt when your loved one has refused your help?
- Or professionals' help?

Families often experience the following feelings:

frustration helplessness
disappointment hopelessness
resentment depression
confusion powerlessness

- B. In the midst of these emotions, families may be inclined to distance emotionally and physically from their loved one. Consequently, the consumer may feel alone and unsupported, which may in turn result in an increase in symptoms. This cycle can be very frustrating for both the individual and family.
- C. Family members may become preoccupied with monitoring the mental status of their loved one and worrying about his/her stability. Consequently, less time and energy are available for taking care of themselves. When families neglect their own needs, they compromise their ability to take care of the consumer.

IV. How to cope when your help is rejected

Distribute Handout X: What To Do When Help Is Turned Away.

- A. Remember that you are not responsible for your loved one's behavior. You are responsible only for your own thoughts, feelings, and behavior.
- B. Remind yourself that your loved one is not rejecting you rather, he/she is having difficulty allowing others to help. Reflect on why he/she may be pushing you away instead of personalizing the behavior.
- C. Seek support for yourself, and continue with your own activities as much as possible.
- D. Calmly express your worry and disappointment to your loved one about his/her choice and the potential implications of it.

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- E. Allow your loved one to face natural consequences of his/her choices (unless he/she is in a dangerous situation).
- F. Remind your loved one of the availability of others who care and could be of help (e.g., hotlines, professionals, other family members, friends).
- G. Remind your loved one of how well he/she was doing when taking the medications and participating in treatment in the past. Emphasize how proud you felt when he/she was happy and making healthy choices. Also share your observation of his/her difficulties since discontinuing treatment. Ask the doctor about the option of injections rather than pills, especially with individuals with schizophrenia. Compliance can be much better with regular injections than with daily pills.
- H. Remain emotionally available to your loved one. Don't give up. Try to be patient.
- I. Ask your loved one if there are any specific ways that you can help.
- J. Remember that mental illness often has ups and downs.
- K. Remember the 3 *C*'s from Alanon: Cause, Cure and Control.
 - You did not cause the mental illness,
 - You cannot cure it,
 - And you cannot control his/her behavior.
 - Ultimately, the decisions are up to your family member.
- L. Note: Excellent resources for further reading on this subject include



- I Am Not Sick, I Don't Need Help (2006) by Xavier Amador, Ph.D.
- Chapter 6 ("Getting the Most out of Medication") and Chapter 7 ("Overcoming the Big *D* Denial) of *The Bipolar Workbook* (2006) by Monica Ramirez Basco, Ph.D. (although this book is focused on bipolar disorder, these two chapters apply to the challenge of medication/treatment compliance for any mental illness).