

DEPARTMENT OF VETERANS AFFAIRS

# Support And Family Education



## *Session Ten – Common Family Reactions to Mental Illness*

### Materials Needed

[Handout S: Help Wanted](#)

[Handout T: Common Family Reactions to Mental Illness](#)

### I. Introduction

*Distribute the following job description ([Handout S: Help Wanted](#)):*

#### *Help Wanted*

*A person willing to work all hours of the day, 7 days a week, no vacation, personal days or holidays.*

*There is no salary, bonus plan, or 401K Plan. There is no supervisor or on-the-job training and no yearly holiday party.*

*You must be emotionally involved with the person you are going to work for, and be willing to work until you are exhausted. You must be a self-starter and entrepreneur. You must also be willing to learn the job by trial and error.*

*The person you are going to care for will frequently not be able to express any appreciation and may even be abusive to you at times.*

*Anyone interested in this job, apply immediately.*

(modified from Scherma, G.A. (2000))

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**Discussion Questions:**

- Does this sound like an appealing job description?
- Yet how many of you do this job every day?

This session focuses on a wide range of emotional responses among family members to a loved one's mental illness. Some may seem familiar to you, while others may not resonate with you.

II. Family response to illness

- A. Coping with a loved one's poor health (physical or mental) is difficult, regardless of the nature of the illness.
- B. Many factors affect how a family responds to changes in health, including the:
1. Family's social-support system
  2. Family's previous experience with and/or knowledge of the illness
  3. Family's coping patterns and resources
  4. Access to and quality of health care
  5. Financial status
  6. Type of onset of the illness (sudden vs. gradual onset, public vs. private, etc.)
  7. Nature of the symptoms
  8. Demands upon families
  9. Consumer's compliance or refusal to participate in his/her care
  10. Course/prognosis of the illness
  11. Others?
- C. However, some factors are specific to a family's experience of a loved one's mental illness.



**Discussion Questions:**

- How is it different for your loved one to struggle with a mental illness versus a physical one?

Possible responses may include:

1. Others' reactions to him/her may be unpredictable and sometimes even hurtful.
2. Family members may feel guilty that they somehow caused the illness or could have prevented it.

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3. Family members may fear others' blaming them for causing the illness.
4. The prognosis and course of treatment are often more concrete with physical illness. There may be more uncertainty and variability with mental illnesses.
5. Some behaviors exhibited by individuals with mental illness can be embarrassing for the family.
6. Doubt about mental health diagnoses (uncommon with physical health diagnoses) may delay consumers/families from accepting a diagnosis, which can postpone treatment.
7. "With greater frequency than for medical diagnoses, mentally ill people will reject medical diagnoses, will refuse to participate in efforts to become well, will be angry and hostile toward families, and will be unable to express gratitude for the care they receive" (Karp & Watts-Roy, 1999, p. 487)
8. Others?

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- **What are the consequences of these differences for families?**

Possible responses may include:

1. Increased sense of isolation and/or "being different," which can result in social withdrawal
2. Fear of telling others about the illness
3. Fear of asking for help
4. Heightened conflict within the family
5. Others?

### III. Stages of emotional responses of families to mental illness

We will review two models that describe family reactions to mental illness. These models are helpful in understanding the process but are not meant to be a treatment strategy. Just as with the popular stages-of-grief model originally described by Elizabeth Kubler-Ross, the stages in the following models are not necessarily sequential or universal. Family members may repeat stages or get stuck in one particular stage. Each family member may respond differently to the mental illness, and members are often at different stages. Gaining some understanding of the various reactions family members experience can ease inevitable tensions and potentially increase acceptance of different responses within a family.

As I present the following models, you may wish to reflect on your personal and family experience of responding to mental illness. Where are you now? Where were you a year ago? Where were you 5 years ago? Are your family members at different stages? Where would you like to be?

*Distribute* [Handout T: Common Family Reactions to Mental Illness.](#)

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A. Dr. Joyce Burland (1990) wrote a family educational curriculum entitled *Family to Family Education Program*. She uses a trauma-based model, conceptualizing the diagnosis of severe mental illness as a trauma for the entire family. She outlines three “Emotional Stages of Response” among family members (Baxter & Diehl, 1998), including:

1. “Heads out of the sand”

- a. This first stage occurs when the family realizes that their loved one has a mental illness. The family unit may deny the severity of the problem and hope that their loved one will “grow out of it.”
- b. At this stage, families need education (especially about prognosis), emotional support, and crisis-intervention services.

2. Learning to cope

- a. In the second stage, families grow in acceptance of the illness, and a variety of emotions may intensify (e.g., anger, guilt, grief, etc.).
- b. During this time, families need opportunities for peer support, education, and skills in self-care and coping with the mental illness.

3. Moving into advocacy

- a. Some families move into advocacy roles as part of their emotional response. Their understanding and acceptance of the mental illness have grown, and they may support other families who are struggling with similar issues.
- b. Families need assistance in maintaining balance in their own lives and assurance from professionals that the mental health system will continue to be responsive to the needs of the consumer and family.

B. The second model was described by Dr. David Karp, a sociologist at Boston College. Based on interviews with many family members about their experiences, he has defined four stages in the “caregiving” experience (Karp & Watts-Roy, 1999; Karp & Tanarugasachock, 2000; Karp, 2001), including:

1. Emotional anomie (before a firm diagnosis)

This stage may include a wide variety of feelings, such as:

- Fear and confusion about the consumer’s behavior
- Uncertainty about how to feel
- Bewilderment about the chaos of the situation
- Questioning of what I did wrong as a mother/spouse/child to cause the illness
- Hope that the behavior will just go away (e.g., midlife crisis; adolescent rebellion; “change of life,” etc.)

2. Hope and compassion (at the time of getting a diagnosis)

The diagnosis can clarify much of the confusion of stage one and may

- Elicit optimism and sympathy in families
- Involve much learning and study about the illness
- Involve hope that a combination of medication, therapy and family love will bring a rapid cure
- Include “heroic measures” to cure the person
- Lead family members to embrace the caregiving role
- Be very reassuring for both the consumer and family, as it can clarify a long history of confusing behavior

Dr. Karp includes quotations from some of his interviews to illustrate these themes:

“I loved getting the diagnosis. That was the best day of my life”  
(mother, age 49); Karp & Watts-Roy, 1999, p. 479

“Well, before she was diagnosed as being bipolar, I was seriously thinking about getting a divorce because she was just so argumentative. You know, after she was diagnosed *it was something*; it was not a character or personality issue. . .it was something that she had no obvious control over and could be treated with medication.”  
(husband, age 50); Karp & Watts-Roy, 1999, p. 480

3. Loss of dreams and resentment (as the family realizes the illness is likely a permanent condition)

During this stage, families may:

- Experience anger and resentment as they feel powerless in changing the consumer’s situation
- Revise their expectations of the consumer
- Experience role reversal (e.g., child taking care of depressed parent)
- Experience resentment when they have to give up their own goals and activities to help the consumer
- Become isolated from their support network because of the demands of dealing with the illness:

“The focus was always on her and her illness, and it wasn’t on me and what I’ve been doing to keep the family afloat and things like that.”  
(husband; Karp & Tanarugsachock, 2000, p. 17)

- Wonder about the consumer’s ability to control his/her behavior and struggle with how to interpret objectionable behaviors. For example, family members may ask, “Do we blame the person or the illness?” for this behavior. Families struggle with the dilemma of loving the person but hating the illness. Families also wonder whether the consumer may be being manipulative at times (e.g., using the illness as an excuse).

“I also got angry because I really view a lot of it as being manipulative, and the older I got, the angrier I got at him (father) because I could see that he could control it when he wanted to...”  
(daughter, age 33); Karp & Watts-Roy, 1999, p. 485

4. Recognition that families cannot control the consumer’s illness, followed by acceptance

As families move into the acceptance phase, they can:

- Feel relieved of a sense of responsibility to fix the problem
- Accept what Karp calls the “4 Cs”: “I did not cause it, I cannot control it, I cannot cure it. All I can do is cope with it” (Karp & Tanarugsachock, 2000, p. 20).
- Gain respect and admiration for the consumer’s struggle and strength

“I’m just in awe of [him] and his abilities to deal with circumstances and to keep a kind of patience, a kind of perspective, and a willingness to work with things...[there is still] intense sadness that he has to do this...that will bring tears to my eyes but [also] an incredible admiration for his attitude toward dealing with it.”  
(Karp & Tanarugsachock, 2000, p. 22)

***Optional: Share a video clip.***

Some videos that portray common family reactions to mental illness include:

*Imagining Robert: My Brother, Madness, and Survival.* (2002). Films for the Humanities and Sciences. Available at [www.films.com](http://www.films.com) or (800) 257-5126.

*The Bonnie Tapes.* The Mental Illness Education Project, Inc. P.O. Box 470813, Brookline Village, MA 02447. (617) 562-1111 E-Mail: [info@miepvideos.org](mailto:info@miepvideos.org). This is a three-part series of videos, including: *Mental Illness in the Family* (26 minutes); *Recovering from Mental Illness* (27 minutes); and *My Sister Is Mentally Ill* (22 minutes). Discussion questions are available for each video at the website.

*Canvas: The Film.* (2007). Portrays schizophrenia and its impact on the family.

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*A Beautiful Mind* (2001). Portrays Nobel-prize winning scientist, John Nash, and his experience with schizophrenia.

*When a Man Loves a Woman*. (1994). Portrays major depression and alcohol abuse and their impact on a family.

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**Discussion Questions:**

- What struck you about the family experiences you saw?
- Have you had similar experiences to the families you saw?
- Could you recognize any of your loved ones in the characters in the video?
- How do you feel about the media's presentation of mental illness?

**IV. Reminders about family reactions**

- A. In this session, we have explored the challenges of dealing with mental illness in a loved one, examined the differences in caring for a loved one with a physical versus mental illness, and reviewed two stage models for family reactions to mental illness.
- B. In closing, we will discuss a few reminders about how families can cope with mental illness.
1. Remember that there is no “right” way to respond and/or cope with mental illness in the family. Work to respect others’ means of dealing with the situation rather than thinking they “should” be doing a certain thing or feeling a specific way.
  2. Be aware that your own feelings and attitudes will likely change over time and that these shifts are normal. Because mental illness is unpredictable, coping strategies that were effective during one episode may not work a year later; therefore, it is important for families to periodically re-assess their boundaries and needs. For example:

“The one thing that I think is trickiest and is very emotional and very stressful is walking that line of ‘what do I do for this person, and what do I not do?’ Because you constantly have to re-evaluate that one...it’s a constant struggle.”

35-year-old daughter (Karp & Watts-Roy, 1999, p. 478)

3. Seek support for yourself. Individuals with mental illnesses go through similar stages and can be irritable and reject your help; they may be

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unappreciative of your support. For example, families commonly struggle over issues of medication compliance, such as a person who reported that her family member would “lash back at me” and say “It’s none of your business if I take my medication” (Karp & Tanarugsachock, 2000, p. 15). At those times, attempt to take a break from interacting with your loved one, engage in some self-care activity, and attempt to discuss the issue at a calmer time.

4. Be a “mirror” not a “sponge.”
  - a. “Sponging” is absorbing another person’s negative feelings and allowing them to control you. For example, if your loved one is feeling depressed and having a really rough day, you, too, become depressed and have a bad day.
  - b. On the other hand, “mirroring” involves simply reflecting back the other person’s negative feelings without “catching” the emotion. Mirroring prevents an over-reaction to the situation and prevents you from taking on the other person’s problems/emotions. For example, if your loved one yells at you for not coming immediately when he/she calls, you simply reflect the issue without emotion in your own voice (e.g., “You are frustrated that I did not answer you right away when you called...”).