

Schizophrenia and the Family

In this module, participants will learn:

- 1) **The many ways in which schizophrenia can affect the entire family, not only the patient.**
- 2) **The vital, yet often unrecognized, role family members play in successful treatment and recovery from schizophrenia.**
- 3) **Increased sensitivity to the experience of family members of patients suffering from schizophrenia.**
- 4) **About evidence-based practices for alleviating the suffering of family members and for aiding in their loved one’s recovery from mental illness.**

Discussion Questions

After completion of the film’s credits, ask the questions which appear below. After each question you will see points to amplify and develop during the discussion.

1. How did Millie’s mental illness affect her children?

- What could her husband, other relatives, or neighbors have done to help?
- What coping strategies and resources are used by each of Millie’s daughters presently?
- How could mental health providers have done more to protect Susan and Tina?
- What reporting obligations are mandatory by law for clinicians, teachers, and others?

2. How did Millie’s mental illness affect her marriage and her husband?

- How might Alan’s response to Millie’s illness been more helpful to her?
- How was Alan affected personally?
- To what degree was Alan’s response to his wife’s odd behavior and attempted suicide a product of the era (i.e., mid 1960's)?

3. Discuss the degree of “insight” or “understanding” each family member had and has into Millie’s illness and needed treatment?

- Susan?
- Tina?
- Tina’s husband Jeff?
- Millie’s brother John?
- Their cousin Nancy?
- Millie’s ex-husband Alan?
- Alan’s second wife, and Susan and Tina’s stepmother?
- Millie, herself?
- How could each family member’s knowledge about Millie’s illness been improved?

4. What role did Millie’s family play in her treatment and progress toward recovery?

- In what ways did Millie’s mother hinder and/or help her daughter’s progress toward recovery?

- In what ways did Alan hinder and/or help Millie’s progress toward recovery?
- What role, if any, did Millie’s brother John and cousin Nancy play?
- What role did Susan and Tina’s obtaining guardianship play?

5. Why is it that Millie has been in the same home and held a job for more than two and a half years now?

- What was Millie’s contribution to her own progress?
- What were Susan and Tina’s contribution to Millie’s progress?
- What role did mental health providers play?
- What role did the group home staff play?
- What role did her employer likely play?

Teaching Points for the Facilitator:

- 1) First and foremost, it is vitally important, if at all possible, to utilize the input of the consumer herself in the process of her own recovery. The President’s New Freedom Commission on Mental Health calls for a transformation of the mental health system so that it becomes “consumer and family driven.” The degree of consumer input should be a function of the degree of disability of the consumer.*
- 2) Those who suffer from the results of mental illness, include not only the person with the mental illness but the family members as well. Millie’s mental illness has had profound effects on her family members throughout the years. For example, her husband could not bear the tension created in the household. He apparently had little information or understanding of the nature of his wife’s illness and that it might have been the cause of her unpredictable moods and post-partum depression. Millie’s brother, John just “checked out” as his way of coping with Millie’s constant disruptions. It is important to recognize the productive and destructive ways in which family members are coping and offer tools to the family for getting help.
- 3) Millie’s illness left her indifferent and often abusive toward her young children. They carry with them, to this day, feelings of anger and great sadness because of the neglect of the neighbors, their grandmother, and even their own father who all “turned a blind eye” to abuse that had occurred over many years. It is important to consider your role as a caregiver in exploring the circumstances of children in the family.
- 4) Millie’s qualities of intelligence, wit and a charming personality have a redemptive quality. These qualities have shown through the often dark, harrowing symptoms of the illness. Over time, understanding the difference in Millie’s personality when she’s ill versus when she’s been treated effectively, may have been a huge motivation for Millie’s daughters to devote energy and resources in trying to help their mother find continuity in her treatment and to helping her adjust to stable living in society.
- 5) Fifty percent (50%) of people with mental illness live with their families.⁽¹⁾ Others, like Millie, transiently move from institutions, to “half-way” houses, from apartment to apartment, and some tragically to the street. In all cases, the illness results in grief, guilt, family disruption and suffering.

- 6) Not long ago, families in such turmoil were also stigmatized and blamed for causing or contributing to their loved one’s mental illness. They were accused and corrected by acquaintances and professionals alike as being overindulgent or indifferent; emotionally over-reactive or avoidant; punitive or lax; and critical or gullible. Many family members painfully accepted blame and tried to follow the advice offered, but even more painfully recognized it had little or no affect on them or their ill family member.

It’s important for the mental health professional to help alleviate a family’s sense of helplessness and guilt. Families need to be reassured and guided in their commitment to their mentally ill loved one. False myths, when present, about what family members might have done to contribute to the illness must be dispelled.

Such morbidity in the whole family requires more adaptive responses from mental health professionals and others not only to lessen family burden but also to enhance quality of life for everyone, including the patient. In fact, recent scientific studies indicate that less than 10% of families of outpatients with schizophrenia receive support or education,⁽²⁾ despite the fact that most mental health professionals believe that such help is very important.⁽³⁾

Since the founding of the National Alliance for the Mentally Ill (NAMI) in 1979, there has been an acceleration of studies of various interventions for patients with schizophrenia and their families which have stressed enhancing competencies not pointing out deficits. It took Susan and Tina so many years to figure out how to care for Millie and deal with their complex personal feelings, in large part because they were not offered any education or resources such as NAMI. They had to learn how to care for Millie by trial and error, and completely on their own.

- 7) In the last 20 years, a number of approaches to address the needs for family support and education have been developed. They include individual family consultation with a mental health professional;⁽⁵⁾ a variety of short term professionally led therapeutic education courses;⁽⁶⁾ and family led education and support groups.⁽⁷⁾⁽⁸⁾ Under the leadership of the World Schizophrenia Fellowship in 1999, a consensus list of the critical elements of these programs was developed.⁽⁹⁾ The list includes 15 principles which have evidence based effectiveness for alleviating the suffering of family members and for aiding in recovery from mental illness of their loved one.

The 15 principles include:

1. Coordinate of the goals and treatment plan of all stake-holders in a collaborative and supportive inter-relationship.
2. Attend to the social as well as clinical (DSM IV) needs of the consumer.
3. Provide evidence-based medication management.
4. Involve family members as partners in planning and delivering treatment.
5. Explore family members expectations of the consumer and of the treatment.
6. Assess family’s strengths and limitations in ability to support the consumer.
7. Help resolve family conflict by being sensitive to their distress.
8. Address feelings of loss.
9. Provide relevant scientific information regarding diagnostic criteria, neuro-pathways, neuro-chemistry, medication actions and side effects, and range of treatment approaches.
10. Provide an explicit, concrete plan for potential crisis situations.
11. Enhance effective communication between family members.
12. Train the family in structured problem solving techniques.
13. Encourage participation in family support groups (NAMI, NMHA, etc)
14. Help meet the unique needs of each family with flexibility.
15. Provide direct and secure bridges of referral to other mental health professionals in the event that current work with the family is interrupted or ceases.⁽¹⁰⁾

Literature Cited

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Guide for Mental Health Professionals & Trainees - Chapter 1 of 5
“Schizophrenia & the Family” – by Edward Foulks, M.D., Ph.D.
Designed to accompany the documentary *Out of the Shadow*

Recommended Resources

NAMI – National Alliance on Mental Illness

www.nami.org

With over 1100 affiliates nationwide, NAMI is a fantastic resource for you, and families with whom you are working. To find out if there is a local NAMI affiliate in your area, see the complete listing on the NAMI National website.

For “**Family-to-Family**” or “**Journey of Hope**” family education support groups, contact your local NAMI affiliate office.

Mental Health America

www.nmha.org