

DEPARTMENT OF VETERANS AFFAIRS

# Support And Family Education



## *Session Four – Schizophrenia and its Impact on the Family*

### Materials Needed

[Handout H: Schizophrenia and its Impact on the Family](#)

Brochures on local treatment options for people with symptoms of schizophrenia

### I. Facts about schizophrenia: Prevalence, development, and course

- A. Schizophrenia is quite common. Approximately 1 of every 100 people in the United States has this disorder. Approximately 2.5 million Americans are living with schizophrenia today, and over 100,000 new cases are diagnosed each year (NIMH, 1990).
- B. Economically, schizophrenia costs the United States over \$60 billion per year in direct treatment costs, including direct healthcare costs, non-healthcare losses, and indirect costs (Wu et al., 2005).
- C. Men and women are equally affected by schizophrenia (Mueser & McGurk, 2004).
- D. The illness occurs at similar rates in various ethnic groups worldwide, regardless of culture, race, and religion (Mueser & McGurk, 2004).
- E. Psychotic symptoms usually emerge in the teens or twenties in men and the twenties or early thirties in women. Symptoms may become better or worse at different times in a person's life (NIMH).
- F. Schizophrenia does run in families. Having a close relative with this disorder increases the risk for developing it. Ten percent of people with a first-degree relative (parent or sibling) who has the illness will develop it. If one identical twin has schizophrenia, there is a 40% to 65% chance that the other twin will as well (Cardno & Gottesman, 2000).

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- G. According to the vulnerability-stress model of the causes of schizophrenia, the severity and course of the disorder are determined by three important factors:
1. Biological vulnerability (due to an imbalance in brain chemistry caused by genetic factors or early biological risks)
  2. Stress
  3. Coping skills
- H. Several subtypes of schizophrenia exist:
1. Paranoid schizophrenia: delusions and hallucinations only, primarily focused on a person's feeling persecuted by some individual or agency
  2. Disorganized schizophrenia: disorganized speech (speech that is irrelevant or "off the subject"), disorganized behavior (behavior that is inappropriate or not effective for independent living), negative symptoms (unresponsiveness, lack of interest, lack of emotional expression)
  3. Catatonic schizophrenia: catatonic behavior (quite rare)
- I. Other diagnoses in the psychotic disorder category include:
1. Brief psychotic disorder
  2. Schizophreniform disorder
  3. Schizoaffective disorder
  4. Delusional disorder
- J. Prognosis is difficult to determine, as many factors affect long-term functioning (e.g., premorbid functioning, participation in treatment, social support). One study reported that, of 2,000 individuals with schizophrenia, 25% fully recovered, 50% at least partially recovered, and 25% required long-term care (NIMH, 1990).
- K. Consistent with the recovery movement, research is revealing the potential for significant improvement for individuals who receive extensive psychological rehabilitation, including assistance with vocational training, housing, and social support (Corrigan, Mueser, Solomon, Bond, & Drake, 2007).
- L. If an individual has schizophrenia, he/she is at greater risk for also having another diagnosis (commonly depression, substance abuse, etc.). For example, the lifetime prevalence rate of substance abuse among persons with schizophrenia is 47% (Regier, Farmer, Rae et al., 1990).

***Optional: Show clip of video, I'm Still Here: The Truth About Schizophrenia (Wheeler Communications) to review information presented so far.***

Dr. Frese (who speaks at the beginning of this video) is a physician and later the director of the psychiatric unit where he had previously received services OR

***Show movie/documentary depicting schizophrenia and its impact on the family, such as: Canvas; A Beautiful Mind; Imagining Robert: My Brother, Madness and Survival; or Benny and Joon.***

## II. Diagnosing schizophrenia

A. The diagnosis of schizophrenia is made only when very specific criteria are met.

1. Various types of schizophrenia exist that are distinguished by different combinations of symptoms. For this reason, one person who has been diagnosed with schizophrenia may appear very different from another individual with the same disorder.
2. The diagnosis can be made only by a trained mental health professional (preferably one with experience in working with schizophrenia).
3. Schizophrenia is often confused with multiple personality disorder, otherwise known as dissociative identity disorder. These disorders are not the same.

B. Some symptoms of schizophrenia (especially delusions and hallucinations) can result from several other sources, such as:

1. Drug-induced psychotic state
2. Dementia
3. Medication side-effects
4. Medical condition
5. Mania (phase of bipolar disorder)

## III. Definitions, effects on the family, and coping strategies for specific symptoms of schizophrenia

Note: Rather than outlining all the specific criteria, we will review the characteristic symptoms of schizophrenia (*DSM-IV*, 1994).

A. Symptom: Individuals may experience delusions or false beliefs.

### 1. Examples

- a. May believe they are Jesus Christ.
- b. May be convinced that the FBI is after them.

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**Discussion Questions:**

- Can you describe any delusions that your family member experiences (or has experienced)?
- How have your loved one's delusions affected your family life?

2. Effects on the family

- a. Because of these false ideas, individuals may distrust and feel paranoid and confused regarding family members. Consequently, family members often feel hurt and frustrated.
- b. The tenacity of the consumer's delusions may render resolution of family conflicts quite difficult. These conflicts may be confusing and frightening for family members.

3. What to do

- a. Avoid discussing details of his/her delusional comments. Do not try to convince your loved one that a belief is wrong or not real (e.g., "Don't be silly – there's nothing to be afraid of!").
- b. If your loved one is agitated, listen calmly and respectfully. Respond by focusing your attention primarily on reality-based remarks.
- c. If strong feelings accompany the delusions, you can address the emotions and offer assistance in coping without commenting on the specific delusion. For example, you may say, "I understand that you feel afraid. I will sit with you for a while until you feel safe."

B. Symptom: Individuals may experience hallucinations or sensory experiences (sound, sight, smell, taste, and touch) with no stimulation from the environment.

1. Examples

- a. May hear sounds or voices that are not heard by other individuals.
- b. May see people or objects that are not present.

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**Discussion Question:** Would you share any of the hallucinations that your family member experiences (or has experienced)?

## 2. Effects on the Family

- a. Family members may have difficulty communicating effectively with consumers who are distracted by delusions and/or hallucinations.
- b. Seeing your loved one talking to him/herself or responding to unseen stimuli can be frightening and confusing.

## 3. What to do

- a. If you see your loved one talking to him/herself, laughing suddenly for no obvious reason, etc., get as much information as you can about how the person is feeling and what will help him/her to feel safe and in control.
- b. Suggest the possibility that the experience is a symptom and part of the illness, without casually dismissing it.
- c. Calmly but firmly remind your loved one of any necessary limits (e.g., “You need to stop screaming.”).
- d. Some families find the use of humor, gentle physical touch, and reassurance to be helpful in grounding and calming their loved one.

## C. Symptom: Individuals may exhibit disorganized speech.

### 1. Examples

- a. May “slip off track” or switch conversation topics at random.
- b. May answer questions in a way that doesn’t make sense.
- c. May use inappropriate or nonsense words.

## D. Symptom: Individuals may exhibit disorganized behavior.

### 1. Examples

- a. May have difficulty in performing activities necessary for daily living (e.g., attending to personal hygiene, cooking, grocery shopping).
- b. May display socially inappropriate behavior (e.g., wearing a coat during hot summer months, masturbating in public, shouting or swearing for no apparent reason).

## 2. Effects on the Family

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**Discussion Question:** How are your interactions with your loved one affected by his/her disorganized speech and behavior?

- a. Because of the consumer's odd speech and behaviors, family members may feel confused and frustrated.
- b. As a result of others' discomfort with the consumer's disorganized speech and behavior, the family may become socially isolated, withdrawing from their support network. Family members may feel embarrassed about their loved one's bizarre behavior in public.

## 3. What to do

- a. Respond to disorganized speech by communicating calmly, clearly, and directly.
- b. Don't worry about being unable to understand the content of your loved one's speech; rather, focus on conveying your respect for the person.
- c. Respond to single thoughts or the emotional tone of the speech.

**Note:** A great deal of research has examined the role of "expressed emotion" in families that have a member with schizophrenia. High levels of expressed emotion (hostility, being overly critical, emotional over-involvement) in these families have been linked to an increased risk for relapse and re-hospitalization. Therefore, family education (e.g., SAFE Program) can be very helpful in making the home environment calmer for the consumer (also, see session on "Creating a Low-Stress Environment and Minimizing Crises").

E. **Symptom:** Individuals may exhibit catatonic behavior.

### 1. Examples

- a. May hold a position without moving for long periods of time.
- b. May mimic the speech or movements of others.

F. **Symptom:** Individuals may exhibit social and occupational difficulties.

### 1. Examples

- a. May have difficulty keeping a job for a long period of time.
- b. May struggle with interpersonal relationships because of deficits in social skills and/or lack of interest in close relationships.

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## 2. Effects on the Family

- a. An individual's difficulty in maintaining employment often causes financial stress for the family.
- b. Spouses may be overwhelmed with responsibilities in caring for the loved one, and feelings of anger and resentment may arise.
- c. Children may assume adult responsibilities at an early age, missing the opportunity to be a "child."

### G. Symptom: Individuals may exhibit negative symptoms.

#### 1. Examples

- a. May fail to respond to others with eye contact and facial expressions.
- b. May speak in a brief and empty fashion with very little emotional expression ("blunted" or "flat" affect).
- c. May show little motivation or interest in participating in work or social activities.

#### 2. Effects on the Family



**Discussion Question:** How have your loved one's negative symptoms (e.g., lack of interest, lack of emotional expression) affected your relationship?

- a. Individuals with schizophrenia may be emotionally unavailable because of preoccupation with their mental stress. As a result, family members may feel rejected and lonely.
- b. Family members often experience these negative symptoms as more disturbing than the other (positive) symptoms (Pollio, North & Foster, 1998).
- c. Unfortunately, psychiatric medications are less effective in treating these negative symptoms of schizophrenia than in decreasing delusions and hallucinations.

## IV. General tips for coping with schizophrenia in the family

*Distribute* [Handout H: Schizophrenia and its Impact on the Family](#)

- A. Educate yourself about schizophrenia through reading, attending lectures, and talking to others in similar situations.

**Good Books on Schizophrenia:**

*The Family Intervention Guide to Mental Illness: What You Need to Know About Symptoms, Therapy, Medication, and Recovery.* (2007). B. Morey and K. Mueser.



*The Complete Family Guide to Schizophrenia: Helping Your Loved One Get the Most out of Life.* (2006). K. Mueser & S. Gingerich

*I'm Not Alone: A Teen's Guide to Living with a Parent Who Has a Mental Illness.* (2006). M. Sherman & D. Sherman. Available at [www.seedsofhopebooks.com](http://www.seedsofhopebooks.com)

*Surviving Schizophrenia: A Manual for Families, Patients, and Providers.* (2006). E. Torrey

*When Someone You Love Has a Mental Illness: A Handbook for Family, Friends and Caregivers.* (2<sup>nd</sup> ed). (2003). R. Woolis.

**Memoirs about Schizophrenia:**

*Tell Me I'm Here.* (1992). A. Deveson. (mother's experience of son with schizophrenia)

*My Mother's Keeper: A Daughter's Memoir of Growing up in the Shadow of Schizophrenia.* (1997). T. & J. Holley.

*The Quiet Room: A Journey out of the Torment of Madness.* (1994). L. Schiller & A. Bennett

*The Day the Voices Stopped: A Memoir of Madness and Hope.* (2001). K. Steele and C. Berman.

**Relevant Web Sites:**

[www.schizophrenia.com](http://www.schizophrenia.com) – Schizophrenia Home Page

[www.mentalhealth.com/book/p40-sc01.html](http://www.mentalhealth.com/book/p40-sc01.html) – Schizophrenia: Handbook for Families

[www.schizophreniadigest.com](http://www.schizophreniadigest.com) – magazine focusing on providing inspiration and information about mental illness

- B. Recognize that your loved one's symptoms have nothing to do with you or your relationship. If you are unable to get your needs for emotional support met with your loved one, foster relationships with others (friends, family, etc.) who can provide that connection.
- C. Do not tolerate abuse. Set clear limits, and ask your loved one to change his/her behavior when acting inappropriately. If he/she does not respond, take steps to protect yourself and others from injury.
- D. Pay attention to warning signs of a potential relapse, including discontinuing medications, insomnia, increased social withdrawal, auditory/visual hallucinations, worsening in personal hygiene, etc.

- E. Communicate honestly and regularly with your loved one's providers. You may be the only person who observes the bizarre behavior, so the information you provide can be very important.
- F. Encourage your loved one to participate fully in his/her treatment by taking medications regularly and attending various therapies.
- G. Choose your battles. Practice being tolerant of annoying behaviors so that you can conserve your energy for dangerous behaviors.
- H. Do not neglect your own needs, as doing so may build resentment toward your loved one.
- I. Take any comments that your loved one makes about suicide or harming others very seriously, and seek professional help immediately.
- J. Notice and praise your loved one's positive behaviors (taking medicine regularly, staying calm when experiencing upsetting hallucinations or delusions, etc.).

## V. Treatment for individuals with schizophrenia

Treatment options for individuals living with schizophrenia have grown considerably in the past decade. With the increasing role of the recovery movement and the creation of new services, there is now much greater hope for people living with schizophrenia than there was before.

Historically, psychiatric medications were often the only treatment for individuals with schizophrenia. However, during the past decade a wide variety of additional services have emerged that have the potential to dramatically improve people's quality of life. Although there is no cure for schizophrenia at this time, consumers who stay on their medications and participate in treatment can lead rewarding, meaningful lives. We will now briefly review various treatment options for people living with schizophrenia:

### A. Psychiatric medications

1. A variety of medications for schizophrenia have been available since the 1950s, and many can reduce the intensity/severity of symptoms (especially hallucinations and delusions).
2. Many different antipsychotic medications are available, each with specific properties and sets of side-effects (including varying risks of tardive dyskinesia: tremors and involuntary movements that develop in some individuals with long-term use of antipsychotic medications).

3. Some medications introduced in the 1990s (e.g., atypical antipsychotic drugs such as Clozaril, Risperidal, Zyprexa) do not produce these tardive dyskinesia side-effects. However, some of these medications require close monitoring by the provider, and they can be expensive. Other medications in this category increase one's risk of gaining weight or experiencing other unpleasant side-effects (such as increased risk for diabetes or high cholesterol).
4. Medications are quite effective in reducing some symptoms (e.g., hallucinations and delusions), but antipsychotic medications alone are not able to prevent repeated relapses. For example, 40% of individuals on antipsychotic medications relapse within 2 years of hospital discharge. However, 80% of consumers relapse within 2 years if they discontinue their medications, so drugs can decrease the frequency of relapse (NIMH, 1990). Further, family involvement in the consumer's treatment can reduce relapse rates (Pfammatter et al., 2006; Pharaoh et al., 2006).
5. It is extremely important that consumers never discontinue these medications without talking with their doctor. Communicating openly with the provider helps him/her manage the medications most effectively.
6. As discussed in Session 10 ("What to do when your help is turned away"), medication compliance can be a major problem for individuals with schizophrenia. Individuals may forget to take their medications; they may believe they are cured and therefore don't need the medicine; they may dislike the side-effects; etc. In fact, approximately half of people taking antipsychotic medications quit after 1 year, and up to three quarters discontinue after 2 years (*The Harvard Mental Health Letter*, July, 1995). Therefore, regular injections of long-lasting antipsychotics (e.g., Prolixin or Haldol) may be helpful with consumers who are experiencing such difficulties.

#### B. Family psychoeducation/education

Empowering families with information about the illness, skills in solving problems and communicating effectively with the consumer, and assistance in managing crises can be very helpful – both for the consumer and family member. Participating in the SAFE Program, a family education model, is a wonderful way of supporting your loved one! In addition, NAMI provides a free 12-week class for family members, titled the Family-to-Family Education Program; this class is facilitated by trained family members. Contact your local NAMI affiliate for more details about programming in your area ([www.nami.org](http://www.nami.org))

#### C. Compensated work therapy/supervised job coaching

Many people with schizophrenia struggle with finding and maintaining suitable, fulfilling employment. Mental health providers can assist consumers in finding job

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training, managing finances, learning how to use public transportation, improving skills in relating to bosses/colleagues, and succeeding in low-stress work environments. Being active in a volunteer or paid position can greatly enhance the individual's self-confidence and self-esteem.

D. Assertive Community Treatment (ACT) teams/Mental Health Intensive Case Management (MHICM) program

These programs typically involve a multi-disciplinary team that works closely with the individual in the community to improve his/her quality of life and decrease the need for frequent hospitalizations. Mental health providers frequently visit consumers in their homes and help manage everyday activities (shopping, cleaning, managing money, taking medications, etc). Often providers work closely with consumers' families as well, supporting them in dealing with their loved one.

E. Self-help groups

Self-help groups, long popular for people dealing with addictions, are gaining recognition for people living with serious mental illness. Often led by individuals with schizophrenia, these groups provide a forum for open sharing and mutual support. NAMI recently created some new peer-support programs, such as Peer to Peer and NAMI Connection. Contact your local NAMI affiliate for more details about programming in your area ([www.nami.org](http://www.nami.org)).

## VI. Review of local treatment options for individuals with schizophrenia

Example: Oklahoma City VA Medical Center

A. Medication management

B. Day Treatment Center/Psychosocial Rehabilitation Program

C. Reaching out to Educate and Assist Caring, Healthy Families (REACH) Project – This 9-month family psychoeducation program provided by the Family Mental Health Program supports veterans and their family members dealing with schizophrenia. The program involves both single-family therapy and multi-family groups/psychoeducational classes. Sessions are held in the evenings to accommodate participants' work schedules.

D. High-Functioning Schizophrenia Group – This bi-weekly group addresses important issues, such as social skills, communication skills, medication compliance, self-esteem, and social support.

***Distribute flyers or handouts describing all available programs for veterans living with schizophrenia***