SAFE Program:
Mental Health Facts for Families

Support And Family Education

18-session family education program for people who care about someone living with mental illness or PTSD

Michelle D. Sherman, Ph.D.
Oklahoma City Veterans Affairs Medical Center
South Central MIRECC
Third Edition
Revised April 2008
Acknowledgments

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Michelle D. Sherman, Ph.D.
Director, Family Mental Health Program, Oklahoma City Veterans Affairs Medical Center
Affiliate Research Investigator, South Central MIRECC
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# Table of Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acknowledgments</td>
<td>vi</td>
</tr>
<tr>
<td>Preface to the Third Edition</td>
<td>vii</td>
</tr>
<tr>
<td>Review of the Literature</td>
<td>1</td>
</tr>
<tr>
<td>Needs Assessment</td>
<td>3</td>
</tr>
<tr>
<td>Needs Assessment Questionnaire for Family Members</td>
<td>4</td>
</tr>
<tr>
<td>Goals of the SAFE Program</td>
<td>5</td>
</tr>
<tr>
<td>Format of the SAFE Program</td>
<td>6</td>
</tr>
<tr>
<td>Materials Needed for Each Session</td>
<td>8</td>
</tr>
<tr>
<td>Overview of Program Sessions</td>
<td>9</td>
</tr>
<tr>
<td>Handout A: Welcome to the SAFE Program</td>
<td>13</td>
</tr>
<tr>
<td>Handout B: Resource List for Families</td>
<td>14</td>
</tr>
<tr>
<td>Documentation and Workload Credit</td>
<td>23</td>
</tr>
<tr>
<td>Publicity Efforts</td>
<td>25</td>
</tr>
<tr>
<td>SAFE Program Pamphlet</td>
<td>28</td>
</tr>
<tr>
<td>SAFE Program Annual Schedule</td>
<td>29</td>
</tr>
</tbody>
</table>
Session Outlines

Information About Disorders

Session One: What Causes Mental Illness
Handout C: What is Mental Illness?
Handout D: Biopsychosocial Model and Vulnerability-Stress Model

Session Two: Depression/Bipolar Disorder and Their Impact on the Family
Handout E: What Can I Do When My Family Member is Depressed?

Session Three: PTSD and its Impact on the Family
Handout F: PTSD and Its Impact on the Family
Handout G: What We’d Like our Family Members and Friends to Know About Living with PTSD

Session Four: Schizophrenia and its Impact on the Family
Handout H: Schizophrenia and its Impact on the Family

Skills for Family Members

Session Five: Communication Tips for Family Members
Handout I: Communicating With Your Loved One
Handout J: Practicing I Messages

Session Six: Limit Setting and Boundaries with Family Members
Handout K: Coping with Mental Illness
<table>
<thead>
<tr>
<th>Session</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Session Seven: Problem-Solving Skills for Families</td>
<td>105</td>
</tr>
<tr>
<td>Handout L: Problem-Solving Skills</td>
<td>112</td>
</tr>
<tr>
<td>Session Eight: Creating a Low-Stress Environment and Minimizing Crises</td>
<td>113</td>
</tr>
<tr>
<td>Handout M: Tips on Creating a Low-Stress Environment and Minimizing Crises</td>
<td>121</td>
</tr>
<tr>
<td>Handout N: Tips on Getting the Most from your Psychiatric Medications</td>
<td>123</td>
</tr>
<tr>
<td>Handout O: Note cards for Role-Plays</td>
<td>125</td>
</tr>
<tr>
<td>Handout P: Resource List for Dealing with Emergencies</td>
<td>126</td>
</tr>
<tr>
<td>Session Nine: What I Can Do When My Family Member Is Angry or Violent</td>
<td>127</td>
</tr>
<tr>
<td>Handout Q: Anger Management – Time-Out Process</td>
<td>133</td>
</tr>
<tr>
<td>Handout R: Referrals for Domestic Violence</td>
<td>135</td>
</tr>
<tr>
<td>The Experience of Caring About Someone Living with Serious Mental Illness/PTSD</td>
<td>136</td>
</tr>
<tr>
<td>Session Ten: Common Family Reactions to Mental Illness</td>
<td>136</td>
</tr>
<tr>
<td>Handout S: Help Wanted</td>
<td>144</td>
</tr>
<tr>
<td>Handout T: Common Family Reactions to Mental Illness</td>
<td>145</td>
</tr>
<tr>
<td>Session Eleven: Taking Care of Yourself</td>
<td>147</td>
</tr>
<tr>
<td>Handout U: Taking Care of Yourself</td>
<td>153</td>
</tr>
<tr>
<td>Session Twelve: Skills for Managing Stress Effectively as a Family Member</td>
<td>154</td>
</tr>
<tr>
<td>Handout V: My Coping Skills Toolbox</td>
<td>158</td>
</tr>
<tr>
<td>Handout W: Everyday Survival and Stress-Busting Kit</td>
<td>159</td>
</tr>
<tr>
<td>Session Thirteen: What To Do When Help is Turned Away</td>
<td>160</td>
</tr>
<tr>
<td>Handout X: What To Do When Help is Turned Away</td>
<td>166</td>
</tr>
</tbody>
</table>
Session Fourteen: Do’s and Don’ts in Helping Your Family Member  
   Handout Y:  Tips by a Panel of Experts on Caring about Someone  
   with a Mental Illness  167  
   Handout Z:  Do’s and Don’ts in Helping your Family Member  
   or Loved One  170  
   Handout AA:  What We’d Like our Family Members and Friends  
   to Know  171  

Dealing with Family, Friends, and Professionals

Session Fifteen: Rights and Responsibilities  
   of Consumers, Family members, and Professionals  174  
   Handout BB:  Rights and Responsibilities  
   of Consumers, Family Members, and Professionals  180  

Session Sixteen: Empowering Your Loved One on the Journey of Recovery  182  
   Handout CC:  Character Strengths  183  
   Handout DD:  My Perception of my Family Member’s  
   Current Functioning  189  
   Handout EE:  Log of Mental Health Treatment  190  

Session Seventeen: What We Tell our Children and Other People  192  
   Handout FF:  What Should We Tell Family Members and Friends?  200  

Session Eighteen: Dealing with the Stigma Surrounding Mental Illness  202  
   Handout GG:  Dealing with Stigma  203  

Program Satisfaction  211  
   Handout HH: SAFE Program Evaluation Form  213  

Treatment Outcome Measurement  214  
   Table One  217  
   Table Two  220
Preface to the Third Edition

Since the first edition of the SAFE Program manual, the field of family intervention and education has grown and changed in many positive ways. The original manual included a quotation describing the inclusion of family members in mental health care as being “fraught with ambivalence at best; neglect or hostility at worst” (Gantt, Goldstein & Pinsky, 1989). Fortunately, positive movement is occurring, moving away from neglect and hostility and ambivalence-induced inertia to action. Several examples are noteworthy.

First, because of the importance and usefulness of family involvement, numerous treatment guidelines now recommend family involvement and education. Several practice guidelines strongly recommend the use of family intervention, including the Schizophrenia Patient Outcomes Research Team (PORT) Treatment Recommendations (Lehman et al., 1998; Lehman et al., 2004), the American Psychiatric Association’s best practice guidelines and the expert consensus guidelines for schizophrenia. Further, the President’s New Freedom Commission Report (2003) recommends that mental health services be transformed to focus more on recovery and consumer/family needs and interests.

Secondly, the recovery movement has begun to open up new possibilities for consumers’ well-being. In this vein, families can be viewed as valued contributors in the consumer’s journey and as supporters in implementing evidence-based treatment plans. For an excellent review of the role of family intervention in the recovery movement, see Glynn et al (2006).

Third, specific evidence-based programs have been created to address the common, complex issue of dual diagnosis—such as the Family Intervention for Dual Disorders (Mueser, Drake, Fox & Noordsy, 2003) and Behavioral Couples Therapy for Alcoholism and Drug Abuse (O’Farrell & Fals-Stewart, 2000; Rotunda, Alter, & O’Farrell, 2001). Other than providing some basic comorbidity information on substance abuse and mental illness, the SAFE Program does not specifically address substance-abuse issues. When the issue arises in session, we discuss treatment options (for both the consumer and family member), but addictions are not a central focus in the program. Clinicians desiring further information and resources on dual diagnosis issues are directed to these two excellent resources.

Fourth, there is growing recognition of the necessity of tailoring family interventions to meet the needs of specific cultural groups. For example, some research has found comparatively high rates of depression among Latino family caregivers of adults with schizophrenia (Magana, Ramirez Garcia, Hernandez & Cortez, 2007), which has implications for intervening with this group. An excellent statement on “cultural competence” relevant to working with families is available in the Substance Abuse and Mental Health Administration (SAMHSA) Center for Mental Health Services’ “Evidence-Based Practices: Shaping Mental Health Services Toward Recovery Toolkit” on family psychoeducation (available online: http://mentalhealth.samhsa.gov/cmhs/communitysupport/toolkits/family/competence.asp). Additional research is needed in understanding the needs of cultural groups and the implications for family intervention.
Despite this tremendous progress, much work remains. Most families are not offered any support or education at all, and research is needed on what families will benefit the most from which type of family intervention. Preliminary work is being done on creating such algorithms for family services (e.g., Cohen et al., 2008), and the VA system is committed to expanding services for veterans’ families in the coming years. As the recovery movement grows and we develop new treatments, let us embrace the challenges and rewards associated with educating, supporting and empowering families as teammates in the journey of recovery.

**Modifications for the Third Edition**

On the basis of feedback from families and clinicians over the past decade, as well as shifts in the conceptualization and provision of care, I have incorporated the following changes in this third edition.

- The psychosocial rehabilitation model and recovery orientation are now imbedded throughout the manual. For example, sessions now provide descriptions of the full array of psychosocial treatment options.
- Information about bipolar disorder and its treatment was added to the session on managing depression.
- References were updated throughout the manual to reflect the latest research on epidemiology and treatment approaches.
- Specific information relevant to Global War on Terrorism veterans is now included, such as research on epidemiology, clinical examples, and treatment options.
- In light of the growth and value of positive psychology, greater attention is now paid to the importance of noticing and celebrating consumers’ strengths. Similarly, the session on managing post-traumatic stress disorder (PTSD) includes information on post-traumatic growth (PTG).
- A new session was added, namely “Empowering Your Loved One on the Journey of Recovery,” which replaces the “Making the Most of your Holiday” session.
- The 18 sessions are organized into four categories (see “Format of the SAFE Program”) to help facilitators in selecting relevant sessions for their participants’ needs. The Resource List was updated with recent books, movies and websites.
Needs Assessment

To tailor the program to your site-specific needs, a needs assessment may be helpful during the planning stages of program implementation. First, discussing the program with colleagues is essential in building a referral source and starting to publicize the program. Colleagues generally express strong support for family programming, and many are willing to assist in the creation and presentation of the series.

Second, asking family members in the various mental health units at the medical center to complete a brief needs-assessment survey can be useful. This assessment process serves a dual function, namely identifying specific interests of the local population and advertising the upcoming program.

Variables assessed in the needs assessment survey include:

- Level of interest in participating in program
- Preferred time of day
- Preferred length of program
- Family member’s diagnosis(es)
- Preference of topics
- Ideas on how to advertise program

Responses to these questions can shape decision making during the planning phase of program implementation.
Needs Assessment Questionnaire for Family Members
Please return to Michelle Sherman, Ph.D., Mental Health Clinic

We are creating some family education programs and would like your input. We want to create a program that will best meet your needs, and would greatly appreciate your taking a few minutes to complete this survey.

1. How interested would you be in attending a program to learn more about your family member's mental illness?

   1  2  3  4  5
   Not at all interested Somewhat interested Very interested

2. What time of day would be best for you?
   ___Morning  ___Lunchtime  ___Afternoon

3. What length of program would you like?
   ___One hour  ___2 hours  ___Over 2 hours

4. What mental illness(es) does your family member have? (Check all that apply):
   ___Anxiety Disorder  ___Post-traumatic stress
   ___Bipolar Disorder  ___disorder (PTSD)
   ___Dementia  ___Schizophrenia
   ___Depression  ___Substance Abuse
   ___Other: ___________________________________________________

5. What topics would you like to learn more about? (please check all that apply):
   ___Information on symptoms of mental illness
   ___Treatment options at VAMC
   ___Do's & Don'ts in helping my family member
   ___Information on medications
   ___How can I take care of myself as a caregiver?
   ___What do I do when my family member talks about suicide?
   ___What do I do when my family member is really angry or violent?
   ___What causes mental illness?
   ___How can I get my family member to take his/her medications?
   ___Other: ___________________________________________________
6. We are planning several means of advertising. How do you think we could let family members know about the availability of these programs?

7. Any suggestions / other comments?

8. Please share with us your address and phone number so we can notify you about upcoming workshops:
   Name: ________________________________
   Address: ______________________________
   Phone Number: _______________________

   Thank you for your input!
Goals of the SAFE Program

The SAFE Program has six major goals:

- To teach family members and friends of individuals with a mental illness about the symptoms and course of mental illness.

- To afford family members the opportunity to ask questions about psychiatric disorders and treatment options (medications, therapies, etc.).

- To reduce the stigma of mental illness by providing a forum in which to discuss concerns and obtain support from peers.

- To publicize the availability of mental health services at the VA Medical Center, including the broad continuum of care.

- To help family members understand the importance of early intervention for their loved one, as well as open, timely communication with providers.

- To link family members with opportunities for support both at the local VA Medical Center and with community resources, including the local NAMI affiliate.
Format of the SAFE Program

Number of Sessions

The third edition of the SAFE Program consists of 18 workshops, organized into four categories:

- Information about disorders
- Skills for family members
- The experience of caring about someone living with serious mental illness (SMI)/PTSD
- Dealing with family, friends, and professionals

Each 90-minute session can stand alone, and the order of presentation of sessions can vary according to participants’ needs. Further, all 18 sessions do not need to be presented, as facilitators can select topics relevant for their participants.

Frequency of Sessions

The series was originally created to be presented once per month. However, experience with the program suggests that the program should be offered on a more frequent basis (such as twice per month). Alternatively, the series can be offered as an 18-week class, or some session information can be condensed into a day-long workshop. The program is flexible to meet site-specific needs.

Participants

Any adult or mature adolescent who cares about someone living with serious mental illness or PTSD can attend the workshops. The individual does not have to be biologically related to the consumer (could be a friend, guardian, case manager, etc.).

The consumers are intentionally not included in the workshops. The program strives to foster a comfortable environment in which participants can freely share their struggles and concerns, without having to worry about possibly offending their loved ones.

Heterogeneity of Mental Illnesses

Family members attending the program have loved ones with quite different mental illnesses, including major depression, bipolar disorder, schizophrenia, PTSD, etc. With the exception of sessions on the specific mental illnesses (PTSD, depression/bipolar disorder, and schizophrenia), the workshops do not focus on a particular diagnostic category, so all participants can relate well to the discussions. In the workshops, family members learn that they have a great deal in common with each other, even if their loved ones and situations may be quite different.
The SAFE program does not focus on dementia or substance abuse. Families dealing with these issues should be given referrals for more specific treatment programs (e.g., Alanon, programs provided through the local Alzheimer’s Association, etc.).

Facilitators

Each session is facilitated by at least two mental health professionals:

- A psychologist, social worker, psychiatrist, psychiatric nurse, or therapist conducts each workshop. One or two core staff should be present at every session, but you can have occasional guest speakers present the didactic material if desired to decrease burden on staff.

- A psychiatrist or pharmacist from the outpatient mental health clinic attends the last 10-15 minutes of each session to answer any questions about medications.

- A NAMI representative attends each session and provides information about the community organization.

- Psychology interns and psychiatry residents are encouraged to attend workshops and co-facilitate sessions. Medical students are also urged to observe sessions to gain some exposure to family services.

- The facility’s recovery coordinator may also participate as his/her schedule allows.

Logistics

Participants are not obligated to attend every session; rather, they are encouraged to attend whichever workshops are of interest to them. Session topics are broad enough to allow discussion of generally applicable information in each workshop. Refreshments are served. There is no cost for the program. If possible, small self-care items (e.g., candles, journals) are given in each session to reinforce the importance of participants’ taking good care of themselves.

A list of the necessary materials for each session is on the next page.

Flexibility

Although each session has a structured format and didactic material to cover, you should remain flexible in meeting the needs of participants. For example, if those in attendance express concerns or questions about a certain mental illness during the check-in process, you may wish to abbreviate the prepared material and devote some time to discussing the more immediate concerns.
Materials Needed For Each Session
SAFE Program

- Participant Notebooks (three-ring binder)
- “Welcome to the SAFE Program” (Handout A, p. 13)
- “Resource List for Families” (Handout B, p. 14)
- “SAFE Program Evaluation Form” (Handout HH, p. 213)
- “SAFE Program Background Information Form” (Handout II, p. 221)
- Flyers and pamphlets detailing upcoming workshops
- Family resource library (books and videotapes family members can borrow)
- Information on the state/local NAMI affiliate
- List of treatment options at your facility (e.g., list of available psychoeducational classes, groups and programs)
- Mental health service newsletter (if available)
- Pamphlets on specific mental illness
- Self-care items for participants (e.g., candle, gift certificate, journal)
- Pens
- Nametags
- Box of tissues
- Refreshments, plates, napkins (if possible)
Overview of Sessions

Before the Session

1. As participants arrive, ask them to complete the “SAFE Program Background Information Form” (see Handout II, p. 221).

2. Encourage participants to enjoy the refreshments and socialize with other participants.

During the Session

Introduction of Facilitators and Welcoming of Participants

1. Introduce facilitators.

2. Thank participants for coming, recognizing the many barriers that they may have had to overcome to attend (e.g., long drive, discouragement from their family members, guilt).

3. Distribute three-ring binder (Participant Notebook) to all new participants. Encourage participants to keep all handouts in this notebook and to bring it to each session.

4. Distribute Handout A: “Welcome to the SAFE Program”
   - Review program goals.
   - Review group guidelines, especially confidentiality.

5. Encourage participants to ask questions at any time during the workshop.

6. Emphasize to participants the importance of mutual respect.

7. Note that each participant has a unique situation
   - You have different relationships with your family member (may be a parent, child, sibling, friend, etc.).
   - Your family members have different mental health problems (e.g., schizophrenia, depression, bipolar disorder).
   - You may have been dealing with the situation for many years or for only a few months.
   - You may have daily interaction with the consumer or only occasional contact.
   - The level of functioning of your loved one may be quite high right now, or he/she may be in a crisis
   - Your ways of coping with your loved one may be quite different from the coping styles of those around you.

In spite of these differences, you share a great deal in common with each other. Much of the learning today may come from each other.
Recognition of the Role of Family Members

Most services provided at the VA Medical Center are designed for veterans. However, this program was created specifically for you, those who care about someone with a mental illness or PTSD.

We want you to know that we value and appreciate your commitment to helping your loved one. We know that living with and/or caring about someone with a mental illness can be very challenging. Your presence here today signifies your desire to know more about how to help them. We applaud all that you do and genuinely thank you for your dedication.

Introductions of Family Members/Check-In

1. Invite family members to introduce themselves, giving their names and the reason for attending today’s session.

2. Participants tend to use this time to update other group members on their current struggles with their loved one. Gently suggest a 5-minute limit per person for the check-in. Do not force participants to share if they prefer to simply listen to the discussion.

Didactic Presentation and Discussion

(See each session outline.)

Note: The length and amount of detail in each session outline vary across workshops. In longer outlines, you may choose to select certain sections relevant to the needs of your participants.

It’s very important that you avoid reading the session content to participants. You can certainly have the manual in front of you, but you should be well versed in the session content so that you can facilitate the session easily. For example, participants may ask questions that you will answer in later parts of the session; feel free to skip to that section and then return to where you left off in the outline. Being responsive and flexible to participants’ needs is very important.

Based on your rapport with the families, engage them in discussion about the material. Share anecdotes and interesting stories to keep participants involved in the discussion. Use of humor can also be a great strategy to maintain interest.

You should solicit questions, reactions and most comments repeatedly throughout the didactic presentation. Realize that it is more important to address issues raised by participants than to get through every item in the outline.
Opportunity To Ask the Psychiatrist/Pharmacist Questions About Medication Issues

Give the psychiatrist/pharmacist the session outline several days in advance so he/she is familiar with the material covered in that workshop. Rather than presenting any formal lecture, he/she addresses any questions or concerns that participants may have.

Brief Overview of NAMI (National Alliance on Mental Illness)

Introduce the representative from the local NAMI, who describes the mission and activities of this organization. He/she also shares information and handouts about advocacy issues and community events pertaining to mental health.

Review of Handouts in Participant Notebook

1. Review the various books, internet addresses, and community resources on the Handout B: “Resource List for Families.”

2. Review the SAFE Program pamphlet listing dates and topics of future workshops and explain that the series has been designed so that participants can either attend all sessions or attend only those of particular interest.

3. Briefly describe the available mental health treatment programs and provide relevant handouts.

4. Review the specific mental health disorders informational pamphlets.

Resource Library

1. Describe available resources (books, videos, etc.) that participants may check out and explain the checkout process.

2. Distribute a list of available books and videotapes that participants may enjoy.

Program Evaluation

Express your commitment to improve this series to better meet participants’ needs. Ask participants to complete the brief evaluation form regarding the session (see Handout HH, p. 213).
Closing

1. Solicit reactions to today’s workshop.

2. Re-emphasize the importance of self-care.

3. Distribute self-care items to participants as a symbol of your appreciation for their commitment to the veterans. Self-care items may include candles, bookmarks, small gift certificates to local restaurants, movie theater tickets, movie rental certificates, crossword puzzle books, journals, etc.

4. Remind participants of next month’s topic and date.

5. Note availability of short time after workshop for individual questions.

6. Thank each participant for coming.
Welcome to the SAFE Program

Support And Family Education,
Mental Health Facts for Families

We're glad that you're here.
We hope this will be a helpful program for you.

Goals:

These workshops are designed to support family members who have a loved one with a mental illness. We hope that these programs will provide opportunities to:

- Learn more about the causes, symptoms, and treatments of mental illness.
- Ask doctors questions in a relaxed environment.
- Recognize early warning signs of problems so you can access services earlier.
- Learn more about what is available at the VA Medical Center and in the community for your loved one and yourself.
- Provide and receive support from other family members who are in similar situations.
- Learn how to take better care of yourself.

Guidelines:

1. We ask that you promise to respect each other's confidentiality by refraining from discussing personal information shared at this workshop. Please feel free to share handouts and educational information, but do not talk about specific participants.

2. Please be attentive, supportive listeners so that everyone can feel heard and respected.

3. Ask any questions at any time. We are here to educate and support you.

Thank you for coming!
We hope to see you next class!

Support And Family Education:
Mental Health Facts for Families
Michelle D. Sherman, Ph.D.
Resource List for Families

Mental Illness (General)

Books:


Websites:
www.nimh.nih.gov - National Institute on Mental Health
www.mentalhealth.com - Encyclopedia of mental health information
www.nami.org - National Alliance on Mental Illness or 1-800-950-NAMI
www.nmha.org - National Mental Health Association or 1-800-969-NMHA
www.allmentalhealth.samhsa.gov - Substance Abuse and Mental Health Services – has special section on overcoming stigma
www.psychologyinfo.com/problems - Psychology Information Online

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Mental Health Facts for Families
Michelle D. Sherman, Ph.D.
Post-Traumatic Stress Disorder (PTSD)

Books:


Websites:

[www.ncptsd.org](http://www.ncptsd.org) - National Center for PTSD

[www.patiencepress.com](http://www.patiencepress.com) - Site with examples of the “Post-Traumatic Gazette”

[www.sidran.org](http://www.sidran.org) - Sidran Traumatic Stress Foundation

[www.trauma-pages.com](http://www.trauma-pages.com) - David Baldwin’s Trauma Information Pages

[www.adaa.org](http://www.adaa.org) - Anxiety Disorders Association of America
Depression

Books:


Websites:

www.depression.org - Comprehensive resources about the latest news and information about depression

www.depressionfallout.com - Help for those that suffer the consequences of dealing with a clinically depressed loved one

www.dbsalliance.org - Depression and Bipolar Disorder Alliance

www.familyaware.org - Families for Depression Awareness

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Phone Numbers:
Depression and Bipolar Disorder Alliance 1-800-82-NDMDA
National Suicide Hotline 1-800-999-9999

Bipolar/Manic Depressive Disorder

Books:


Available at www.seedsofhopebooks.com


Websites:
www.bipolarworld.net - Bipolar world, includes support and educational information

www.dbsalliance.org - Depression and Bipolar Support Alliance

www.mhsanctuary.com/bipolar - Bipolar disorder sanctuary contains information and support

Phone Numbers:
Depression and Bipolar Support Alliance 1-800-82-NDMDA
Schizophrenia

Books:


Websites:
- [www.schizophrenia.com](http://www.schizophrenia.com) - Comprehensive resources about the latest news and information about schizophrenia
- [www.schizophreniadiigest.com](http://www.schizophreniadiigest.com) - Journal providing inspiration and information about mental illness

Substance Abuse

Books:


Websites:
- [www.alcoholics-anonymous.org](http://www.alcoholics-anonymous.org) - Online Recovery AA Resources
- [www.al-anon.alateen.org](http://www.al-anon.alateen.org) - Al-Anon Family Group Headquarters

Phone Numbers:
Al-Anon Meeting Information 1-888-425-2666 (888-4AL-ANON)
Anxiety Disorders

Books:


Websites:
www.adaa.org - Anxiety Disorders Association of America: resources for consumers and professionals

www.freedomfromfear.org - Freedom From Fear – includes overview of anxiety disorders and depression

Personality Disorders

Books:


Websites:
www.BPDCentral.com - Borderline Personality Disorder Web Site

personalitydisorders.mentalhelp.net - Mental Help Net – Personality disorders
For Children


*Bart Speaks Out: Breaking the Silence on Suicide.* (1998). L. Goldman. Los Angeles: Western Psychological Services. (the family dog talks about his feelings when its owner commits suicide) (Currently available only through Western Psychological Services, 800-648-6857).


Support And Family Education:
Mental Health Facts for Families
Michelle D. Sherman, Ph.D.
Autobiographies

Depression


Bipolar / Manic Depressive Disorder


Schizophrenia


Substance Abuse
Other Helpful Websites

www.caregiver.org - Family Caregiver Alliance

www.psych.org - American Psychiatric Association

www.safemedication.com - Provides easy-to-understand information about medications

www.supportpath.com - Support groups and chat rooms for patients and family members

www.healthyplace.com - Communities/support groups regarding mental illness

www.va.gov - United States Department of Veterans Affairs
**Documentation and Workload Credit**

**Rationale for Separate Documentation**

Since the inception of the SAFE Program in Oklahoma City in 1999, the following procedures have been used to capture workload and document care provided to veterans’ family members/friends.

Clinicians do not document the family member’s visit in the veteran chart. Clinicians may choose to include “refer to the SAFE Program/family education” as part of the veteran’s treatment plan, but all documentation of family participation in SAFE is done separately. In this way, the veteran does not have access to information about the family member, thereby allowing families to share freely about their experience without fear of consequence.

**Creation of a Clinic**

The MAS department can create a clinic to be used specifically for the SAFE Program. It is important that the clinic be created as a “non-billable” clinic, but one that generates workload credit. This task should be done during the planning stages of family programming and definitely before the first class.

**Creation of a Collateral Chart**

1. At the family member (collateral)’s first visit, collect the following information (typically by asking him/her to complete a short form):
   a. Collateral’s first and last name
   b. Collateral’s full social security number
   c. Collateral’s date of birth
   d. Collateral’s mailing address
   e. Veteran’s first and last name
   f. The last four numbers of the veteran’s social security number

2. After the session, provide this information to the MAS clerk, who then creates the collateral chart.

**Completing the Encounter and Progress Notes**

1. Create the appointment in the designated clinic and completes the check-out / encounter (in the same process as used with veteran appointments). For SAFE, the following information can be used:
   a. CPT code = 90887
   b. Diagnosis = V65.0 (“healthy person accompanying sick”)
2. Write a progress note for each collateral visit. General information describing the session content and a brief summary of the collateral’s situation can be described.

3. Include the following disclaimer at the end of every SAFE Progress note:

   All non-veteran participants are reminded that they are not eligible for individual mental healthcare at this VA Medical Center. They are instructed to report to their local emergency room or the Oklahoma Department of Mental Health and Substance Abuse Crisis Center if feeling like they are a danger to themselves or others. Any treatment that they receive therein will be at their own expense.

4. You may choose to use/adapt this progress note template:

   TITLE: Family Education  
   DATE OF NOTE: FEB 11, 2007  
   ENTRY DATE: FEB 11, 2007  
   AUTHOR: SHERMAN, MICHELLE D  
   EXP COSIGNER:  
   URGENCY:  
   STATUS: COMPLETED  

   Patient seen for 90-minute education class.

   Family Educational Workshop

   Family member attended a workshop today as part of the:
   SAFE Program - Support and Family Education: Mental Health Facts for Families

   The topic of today's workshop was: What causes mental illness?

   Family member’s level of participation in session: Active

   Date of the next family education program workshop: Mar 10, 2007

   Other comments: Mary attended the SAFE Program for the first time today. She shared that her husband, Tom, has bipolar disorder, and she’s eager to learn more about how to support him. She heard about the SAFE Program through the Day Treatment Program. Today’s session involved a discussion of the causes of mental illness, the biopsychosocial model and the vulnerability-stress model. Several relevant handouts were provided.

   Participants had the opportunity to ask Dr. Faruque questions about medications. A small candle was provided to each person as a small gift.

   All non-veteran participants are reminded that they are not eligible for individual mental health care at this VA Medical Center. They are instructed to report to their local emergency room or the Oklahoma Department of Mental Health and Substance Abuse Crisis Center if they feel like they are a danger to themselves or others. Any treatment that they receive therein will be at their own expense.

   Veteran's Name: Tom Jones
   Veteran's last 4: XXXX
Publicity Efforts

The truism, “If we build it, they will come,” simply does NOT apply to family programming! Of all the tasks associated with preparing for and implementing family education, publicity requires the most creativity, time, and persistence. Many sites have invested large amounts of resources, time, and energy to create family programming, only to be disappointed by low participation. While a full analysis of the barriers to family engagement is beyond the scope of this manual, some creative approaches have been described in the literature (e.g., Dixon et al., 1999; Glynn et al., 2006; Sherman & Carothers, 2005; Sherman, Fischer, Bowling, Ridener & Harrison, manuscript in preparation, 2007).

Publicizing the SAFE program is an ongoing effort. It’s helpful to have several champions—preferably in each mental health unit—who can help create referrals. The facility recovery coordinator can also increase awareness of the program.

Three handouts are used to promote this series:

- SAFE Program pamphlet
- SAFE Program annual schedule
- SAFE Program monthly flyer

Information is disseminated to three sets of people:

- To eligible family members
- To veterans enrolled in mental health treatment programs
- To VA Medical Center and community providers who can share this resource with families

Program Information for Family Members

1. Informational letters were sent to all family members who had completed the needs assessment. (See “Invitation Letter,” p. 31).

2. A pamphlet is given to family members and friends of veterans upon a veteran’s admission to the inpatient psychiatric unit. Social workers and psychiatric residents also share information with family members upon the veteran’s discharge from the unit.

3. Reminder letters are sent 1 week before each session to family members who have attended a SAFE Program workshop in the past 6 months. (See “Reminder Letter,” p. 32).
Program Information for Veterans (Veterans are asked to share this resource with family members or friends who may be interested)

1. The following information is placed on the bottom of all appointment letters from the outpatient Ambulatory Mental Health Clinic:

*******************************************
New SAFE Program for Family Members Only
Support And Family Education: Mental Health Facts for Families

Monday, March 8, 2:30-4:00pm, GA104
This month’s workshop: "What causes mental illness?"
No reservation needed
Call Dr. Sherman for additional information: (405) 270-5183
*******************************************

2. The availability of the program is announced, and pamphlets are distributed during the first week of the Ambulatory Mental Health Clinic’s monthly psychoeducational classes (e.g., Depression Management, Anxiety Management).

3. Brief presentations are made regularly in various mental health programs (including the PTSD Program, Substance Abuse Program, Day Treatment Center).

4. Regular presentations are provided for the Mental Health Consumer Council.

5. Flyers are posted throughout the medical center several days before each workshop.
Program Information for VA Providers and Other Referral Sources

1. Informational letters and pamphlets were distributed to many VAMC providers in the early stages of program development. Annual schedules are also disseminated to educate staff about the program.

2. A brief overview of the program was presented to the primary care providers at the medical center.

3. A presentation to the Patient Education Committee informed them of the nature of the SAFE program.

4. Articles have been published in various newsletters, including the newsletter of the state psychological association, the MIRECC Communique electronic newsletter, and local psychology service electronic meetings.

5. Home health aid providers were given information about the program because of their frequent and possibly intense interactions with family members.

6. Every year, pamphlets, monthly flyers, annual schedules, and invitational letters are distributed to:
   
   a. All psychology and psychiatry service associates
   b. Primary care team patient care managers
   c. Psychiatric nurse specialists
   d. Chaplain service
   e. Patient advocates
   f. Medical and psychiatric social workers
   g. Suicide prevention coordinator
   h. Recovery coordinator
   i. VAMC staff (both outpatient clinics and residential facilities)
   j. NAMI affiliate
   k. Oklahoma City Mental Health Consumer Council (state-based organization)
   l. Oklahoma City VA’s Mental Health Consumer Council

7. Monthly flyers and annual schedules are posted in:
   
   a. Outpatient mental health clinic waiting room
   b. Chapel
   c. Inpatient psychiatry area
   d. Day Treatment Program
   e. Primary care area bulletin boards and waiting areas
   f. Emergency room bulletin board
In the United States, one in four families has a loved one who has a mental illness. Coping with emotional problems due to mental illness and trauma can be very stressful. The Family Mental Health Program of the Oklahoma City VA Medical Center wants to support you.

The SAFE Program, **Support And Family Education**, Mental Health Facts for Families, is a monthly 1½-hour confidential workshop for family members and friends. There is no cost associated with participating in the program. All adult and adolescent family members are welcome.

Attending the SAFE Program provides opportunities to:

- Talk to other family members in similar situations
- Learn about the causes, treatments, and medications for emotional problems
- Receive emotional support and encouragement
- Ask doctors questions
- Improve your ability to take care of yourself

2008 Schedule for SAFE Program
2:30 – 4:00 pm
Room GA-104

<table>
<thead>
<tr>
<th>Date</th>
<th>Topic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jan. 14</td>
<td>Taking care of yourself</td>
</tr>
<tr>
<td>Feb. 11</td>
<td>Depression/bipolar disorder and their impact on the family</td>
</tr>
<tr>
<td>Mar. 10</td>
<td>Limit setting and boundaries</td>
</tr>
<tr>
<td>April 14</td>
<td>PTSD and its impact on the family</td>
</tr>
<tr>
<td>May 12</td>
<td>What I can do when he/she is angry or violent</td>
</tr>
<tr>
<td>June 9</td>
<td>Do’s and don’ts in helping your family member</td>
</tr>
<tr>
<td>July 14</td>
<td>Common family reactions to mental illness</td>
</tr>
<tr>
<td>Aug. 11</td>
<td>What causes mental illness</td>
</tr>
<tr>
<td>Sept. 8</td>
<td>What we tell our children and other people</td>
</tr>
<tr>
<td>Oct. 20</td>
<td>PTSD and its impact on the family</td>
</tr>
<tr>
<td>Nov. 10</td>
<td>Skills for managing stress effectively</td>
</tr>
<tr>
<td>Dec. 8</td>
<td>Problem-solving skills for families</td>
</tr>
</tbody>
</table>

No Reservations Needed
Confidential -- No Charge
May Attend Any Sessions That Are of Interest

For more information, please contact Dr. Sherman, Director, Family Mental Health Program
(405) 270-5183
“Taking care of yourself does not mean doing it all alone.”

-Shakti Gawain

Do you have a family member or friend who has emotional problems or has experienced trauma?

You are not alone…

Support And Family Education

SAFE Program
Mental Health Facts for Families
Oklahoma City VA Medical Center

Created by Michelle Sherman, Ph.D.
Director, Family Mental Health Program
Revised Oct., 2007
SAFE Program

Support And Family Education:
Mental Health Facts for Families

2008 Schedule

Monthly workshops for family members
2nd Monday of each month, Room GA-104, 2:30-4:00pm
No reservation needed
Call Dr. Sherman (270-5183) for more information

Jan. 14  Taking care of yourself
Feb. 11  Depression/bipolar disorder and their impact
Mar. 10  Limit setting and boundaries
April 14  PTSD & its impact on the family
May 12  What I can do when he/she is angry or violent
June 9   Do’s and don’ts in helping your family member
July 14  Common family reactions to mental illness
Aug. 11  What causes mental illness
Sept. 8   What we tell our children and other people
Oct. 20  PTSD and its impact on the family
Nov. 10  Skills for managing stress effectively
Dec. 8   Problem-solving skills for families
Do you have a family member or friend with mental illness?
Do you sometimes feel like no one understands?
You are not alone…

Educational workshop for family members:

**PTSD and Its Impact on the Family**

**Monday, April 14, 2008**

2:30 – 4:00 pm  Room GA-104

Confidential
No charge
No reservations needed

The SAFE Program
Dr. Sherman, (405) 270-5183
Family Mental Health Program
Invitation Letter

February 1999

To Family Member:

Thank you for completing the Family Education Needs Assessment. Family members indicated high levels of interest on the surveys.

This series, entitled the SAFE Program: Support And Family Education, Mental Health Facts for Families, is designed especially for you. Living with and/or helping a family member living with a mental illness can be a difficult and stressful experience, and the Family Mental Health Program wants to support you and provide some educational opportunities.

Starting March 8, 1999, monthly workshops specifically for family members of veterans who have a mental illness will be presented. The seminars will last 1.5 hours, allowing half of the time for a brief presentation and the other half for questions/answers and discussion. Please see the enclosed flyer for a description of the topics. At least two mental health professionals will be present to answer your questions, as well as a representative from the Oklahoma affiliate of the National Alliance on Mental Illness, or NAMI, an organization that provides support and advocacy services for people living with mental illness.

The workshops will be held on the second Monday of each month from 2:30-4:00 pm in room GA 104/105, which is located outside the blue doors of the mental health clinic (ground floor). You are welcome to come every month or only to those sessions with topics of interest to you. There is no charge for any of these workshops. They are for family members only.

I hope that you will consider attending our first meeting on March 8. Please call me if you have any questions or concerns about this program (405-270-5183). I believe this will be a very valuable and informative program for families.

Sincerely yours,

Michelle D. Sherman, Ph.D.
Clinical Psychologist
Director, Family Mental Health Program
Reminder Letter

November 2007

To family members who have attended recent SAFE programs:

I hope you are enjoying the workshop series, the SAFE Program: Support And Family Education, Mental Health Facts for Families. I am very pleased that family members are returning, and I hope to continue to provide helpful information and discussions.

I am writing to remind you of the date of our next meeting. We will meet again in the same room (GA104/105) on:

Monday, December 10, from 2:30-4:00 pm.

Topic of this month's workshop is:

“PTSD and Its Impact on the Family”

Please invite other family members or others you know who may benefit from this series. Please call me if you have any questions or concerns (405-270-5183). I look forward to seeing you on the 10th.

Refreshments will be served!

Sincerely yours,

Michelle D. Sherman, Ph.D.
Clinical Psychologist
Director, Family Mental Health Program
I. Definition of mental illness

_Distribute Handout C: What is Mental Illness?_ (Bisbee, 1991)

1. Every organ in the human body has a function, and numerous problems can arise with each organ. The specific problem with the organ and the resultant disorder dictate the appropriate treatments. This chart places mental illness in the context of other forms of illness.

2. Mental illness is brain dysfunction, affecting:

   a. **Perception** – People may experience the world with their senses (vision, smell, taste, touch, hearing) in unusual and/or strange ways (e.g., hearing voices, seeing things that others do not see).

   b. **Thinking** – Thoughts may occur very quickly/slowly, may be poorly organized, confusing, illogical, irrational, etc.

   c. **Mood** – All human beings experience a variety of moods (e.g., depression, anxiety, mania) and mood changes. Mental illness can emerge when symptoms cause significant distress over time and impair one’s ability to function in daily life.
d. Behavior – People’s behavior may be quite bizarre and confusing for those who do not understand mental illness (e.g., someone with PTSD hiding in the closet when he/she hears helicopters; an individual with obsessive-compulsive disorder checking the stove 20 times before leaving the house; a depressed individual lying in bed for days at a time)

3. Effective treatment of mental illness includes a combination of several elements: medications, healthy life style, consumer and family education, job training/coaching, peer support, and psychotherapy.

II. Categories of mental illness

Many different classification systems for mental disorders exist, but some general categories include:

*Write on board (and very briefly define each disorder):*

- Schizophrenia
- Major depressive disorder
- Bipolar disorder/manic-depressive disorder
- Anxiety disorders (including PTSD)
- Substance-use disorders
- Organic disorders (e.g., Alzheimer’s disease)
- Personality disorders

III. Causes of mental illness

*Given the limited time and the fact that participants' family members have different mental illnesses, discuss overall themes in the causes of mental illness, rather than addressing the specifics of each disorder. Make time available at the end of the session for specific questions.*

**Discussion Question:** What are some commonly held beliefs about the causes of mental illness?

*Examples:*

1. Mental illness does not exist.
2. Mental illness is a normal response to a sick society.
3. Mental illness is caused by the devil, demons, or turning away from God.
4. Mental illness is caused by poor parenting.
5. Mental illness is caused by being lazy and weak.
6. Mental illness is caused by poor family communication
7. Others?

A. Over the years, different theories have been proposed regarding the causes of mental illness. Myths such as these develop because people need an explanation for confusing behaviors. The myths can be transmitted down through many generations without being checked for accuracy. Sometimes myths are a means of denial or of avoiding responsibility for mental illness in a family.

B. What science does know:

*Distribute Handout D: Biopsychosocial Model and Vulnerability-Stress Model (adapted from Bisbee, 1991)*

1. Biopsychosocial model: Mental illnesses have several dimensions that are helpful to review.

*Write on board: Bio, Psych, Social*

*Explain that each area can contribute to an individual’s level of risk for developing a mental illness.*

**BIO** → biology – Refers to the structure of the brain, chemicals in the brain, genes inherited from parents, etc. Science is gaining more knowledge about the large influence of biology on the risk for acquiring a mental illness.

**PSYCH** → psychology – Refers to personality, personal beliefs, thoughts, experiences, etc.

**SOCIAL** → sociology – Refers to environmental stress (e.g., trauma of war, assault), cultural factors, discrimination, etc.

**Therefore** ... Treatment needs to be aimed at all three of these areas:

**BIO** → medication, nutrition, general physical health

**PSYCH** → education (SAFE Program), psychotherapy, coping skills

**SOCIAL** → environmental management, stigma of mental illness, advocacy
2. Vulnerability-stress model

a. One can inherit a predisposition or increased vulnerability (diathesis) to a certain illness (or class of illnesses). The importance of family history with some medical problems (e.g., cancer) is well known. Investigating family history with mental illness can similarly provide very valuable information. Having a family history of a mental illness does not mean you will necessarily get the illness, but you do have an increased risk.

Example: schizophrenia:
1% incidence in general population
10% if a first degree relative (parent, sibling) has the disorder

Fraternal twins: 10-15% incidence rate
Identical twins: 40-65% incidence rate (Cardno & Gottesman, 2000)

Precisely what is inherited that makes a person more likely to get schizophrenia is still unknown, but research continues to study the various causes of mental illnesses.

b. In addition, life experience (stress) can trigger the emergence of a mental illness. All people struggle to cope with major life events; however, individuals with a predisposition for mental illness can have a harder time with the event, and some symptoms of mental illness may emerge.

Discussion Questions:

- Do you have any questions about either model?
- Do you have questions about the causes of any specific disorder(s)?
### What is Mental Illness?

<table>
<thead>
<tr>
<th>Organ</th>
<th>Function</th>
<th>Disorder</th>
<th>Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eyes</td>
<td>Vision</td>
<td>Blurred vision</td>
<td>Glasses, Contacts, Laser surgery</td>
</tr>
<tr>
<td>Ears</td>
<td>Hearing</td>
<td>Deafness</td>
<td>Hearing aid</td>
</tr>
<tr>
<td>Pancreas</td>
<td>Insulin production</td>
<td>Diabetes</td>
<td>Insulin, Diet, Healthy life style, Consumer education, Family education</td>
</tr>
<tr>
<td></td>
<td>Glucose metabolism</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brain</td>
<td>Perception, Thinking, Mood, Behavior</td>
<td>Mental Illness</td>
<td>Medication, Healthy life style, Consumer education, Family education, Psychotherapy</td>
</tr>
</tbody>
</table>

Biopsychosocial Model

Three factors are important to examine in understanding mental illness:

- **BIO** = biology
- **PSYCH** = psychology
- **SOCIAL** = sociology

**Causal Factors**

- Biology (genes, chemicals, structure) – inherited at birth
- Psychology (personality, beliefs, behaviors, life experiences)
- Sociology (stress from environment, cultural issues such as discrimination, racism, etc.)

**Treatment**

- Biology
  - Taking medication as prescribed
  - Eating a healthy diet
  - Maintaining good physical health and regular exercise
- Psychology
  - Participating in psychotherapy or other classes
  - Learning good coping skills
  - Learning about mental illness
- Sociology
  - Combating stigma
  - Minimizing stress from environment

**Vulnerability – Stress Model**

Individuals can inherit a genetic predisposition (vulnerability) to mental illness, given a family history of some disorder(s).

Then life experiences (stress) can trigger the onset of a mental illness. Individuals with a predisposition for mental illness can have a harder time with major life events, and some symptoms of mental illness may emerge.

Materials Needed:
Handout E: What Can I Do When My Family Member Is Depressed?
Brochures on local treatment options for people dealing with depression and bipolar disorder

I. Symptoms and course of depression
   A. Everyone feels depressed or down at times; however, major depression is more than just feeling the “blues” every once in a while. Each person’s experience of depression is unique.

Discussion Questions:

- What are some symptoms of depression?
- Which are most difficult for you to cope with?

1. Feeling sad, blue, or down
2. Losing interest in previously enjoyed activities
3. Experiencing a change in appetite or weight
4. Having a change in sleep patterns
5. Feeling tired and fatigued OR feeling restless
6. Feeling worthless or guilty
7. Having trouble concentrating, thinking, or making decisions
8. Having thoughts of death or suicide
B. The diagnosis of a major depressive episode is made when a person experiences five or more of these symptoms that occur nearly every day for at least 2 weeks – with at least one symptom being depressed mood or loss of pleasure in previously enjoyed activities (DSM-IV).

C. Approximately 6.6% of the nation (13-14 million people) suffers from some type of depression every year (Kessler, Berglund, Demler et al., 2003). It is often called the “common cold” of mental illness. Many famous people have struggled with clinical depression, including television reporter, Mike Wallace; British prime minister, Sir Winston Churchill; Diana, Princess of Wales; comedian Drew Carey; singer/songwriter John Denver; writer Charles Dickens; singer Mariah Carey; musician Billy Joel; talk show host Oprah Winfrey; tennis star Monica Seles; comedian Chris Farley; musician Sting; and Academy-Award-winning actor, Rod Steiger.

D. According to a large community study, the prevalence of major depression in adults is approximately 16%, making it one of the most common psychological disorders. The average duration of an episode is 16 months (Kessler et. al., 2003).

E. The lifetime incidence of major depression for women is 20% and for men is 12%. Also, people living in poverty are approximately four times more likely to suffer from chronic depression than more affluent people (Kessler et al., 2003).

F. Depression also tends to be recurrent, as over 80% of individuals with depression experience another episode (Mueller et al, 1999), many within 1 year (Coryell et al., 1994).

G. Often an individual with major depression also has another psychiatric disorder. For example, one large study found that almost ¾ of people with major depressive disorder also met criteria for another disorder (commonly anxiety disorders and substance-use disorders) (Kessler et al., 2003).

H. Because of the very nature of depression (decreased concentration, decreased motivation, social withdrawal, fatigue, etc.), individuals are often less productive in the workforce. In fact, US workers with depression cost employers approximately $44 billion per year in lost productive time (Stewart et al., 2003). Depression has been described as the leading cause of disability in the United States and many other developed countries.
II. Symptoms and course of bipolar disorder (also known as manic depression)

A. Another kind of depression involves large mood swings in which consumers go from feeling depressed/sad to quite happy (or irritable). These mood swings are different from everyday fluctuations in mood, as everybody has their “up” and “down” days. These changes in mood are dramatic and interfere with the person’s ability to manage his/her emotions; they often affect relationships and work functioning as well.

B. Approximately 5.7 million American adults (~2.6% of adults) in any given year have bipolar disorder (Kessler, Chiu, Demler, & Walters, 2005).

C. People living with bipolar disorder alternate between periods of depression (symptoms listed above) and episodes of mania. Although each person’s experience of mania is different, some common symptoms (DSM-IV) include:

1. Feeling “high” or “on top of the world” or having an “overly” good mood (Note: some people feel irritable instead of happy.)
2. Needing less sleep than usual
3. Being more talkative than usual and/or with pressured speech (this is often more obvious to other people that to the consumer him/herself)
4. Having racing thoughts and/or jumping quickly from one topic to another
5. Being easily distracted
6. Demonstrating excessive productivity (e.g., cleaning the entire house, being very productive on work projects) and/or being more agitated than usual
7. Pursuing risky activities that can have bad consequences (e.g., spending a lot of money, illicit sexual behavior, gambling)

D. Men and women tend to experience bipolar disorder at approximately the same rate, and the age of onset tends to be similar (Kawa et al., 2005).

E. Both men and women living with bipolar disorder are at increased risk for abusing alcohol and drugs (Hendrick, Altshuler, Gitlin, Delrahim, & Hammen, 2000); they are also more apt to also have anxiety disorders such as PTSD (Mueser, Goodman, Trumbetta, Rosenberg, Osher et al., 1998).

III. What causes depression

A. No one single factor causes depression. Often it is impossible to determine one specific cause of a person’s illness. The constellation of causes is unique to each individual.

B. Family members and friends need to remember that depression is not a person’s fault.

C. Several causes are common:

1. Certain life events may trigger a depressive episode (e.g., death of loved one, retirement).
2. A strong genetic factor is present in many cases of depression and bipolar disorder.
   - If one identical twin has major depression, the other twin has an approximately 37% chance of developing depressive symptoms sometime in his/her life. (Sullivan, Neale & Kendler, 2000).
   - If one identical twin has manic-depression, the other twin has a 40-70% chance of developing the disorder (Craddock & Jones, 1999).
3. Depression may be caused by an imbalance in the level of chemicals in the brain. Many antidepressants work by regulating the levels of these chemicals (neurotransmitters).
4. Medical illness may contribute to the emergence of depression.
5. Use of certain medications may cause depressive symptoms (e.g., some anticonvulsants or thyroid hormones).
6. Excessive use of alcohol and other drugs may contribute to depression, as alcohol acts as a depressant on the central nervous system. Further, substance abuse complicates the diagnosis and treatment of the underlying psychiatric disorder(s).
IV. **The impact of depression on relationships**

**Discussion Questions:**

- How does your loved one’s depression affect your relationship?
- Your family life?
- Your view of yourself?

A. Depression affects a person’s behavior and style of communication (less eye contact, slower and softer speech, negative thinking, reduced problem-solving abilities).

B. Depression is often accompanied by an increase in marital tension and arguments.

C. Depressed people have greater difficulty interacting with others. Therefore, the social life of the couple/family may be altered.

D. Some depressed people are unable to work. Therefore, other family members may have to get a job for the first time or work two jobs to compensate for the reduced income.

E. Family members often become frustrated with the depressed person’s behavior, thinking the consumer should just “get over it” or “cheer up.”

F. Depressed people often have decreased interest in physical intimacy and sexual activity. Partners often worry that the consumer is no longer physically attracted to them, which can increase the tension in the relationship.
V. Important issues surrounding suicide (parts adapted from Woolis, 1992)

FACILITATOR NOTE: As these issues may be difficult to discuss, you may wish to normalize any anxiety when talking about these issues. Also, you may choose to include your facility’s suicide prevention coordinator in this session, as he/she likely has considerable expertise in dealing with issues of suicidality.

A. Many family members worry a great deal that their loved ones may try to kill themselves.

1. Individuals with mental illness commit suicide at a rate that is considerably higher than that of the general population.
2. Over 90% of suicides are associated with a mental disorder or substance-abuse problem (often in combination) (Moscicki, 2001).
   a. More specifically, one third of all clinically depressed people attempt suicide (www.psychiatry.medscape.com/reuters/prof/2000/05/05.15).
   b. According to the National Strategy for Suicide Prevention, about 6-15% of people diagnosed with schizophrenia end their lives via suicide. (www.mentalhealth.samhsa.gov).
3. Men are four to five times more likely to complete suicide than women. Women are three times more likely to attempt (but not complete) suicide than men (Moscicki, 1995).

B. People consider and attempt suicide for many reasons, including the following:

1. Some make a decision to end their lives – they are very unhappy with their lives and feel hopeless that the situation will improve.
2. Some engage in reckless behavior because they don’t think they will die (e.g., jump off a tall building believing they are super-human). Their judgment is impaired, and they may not understand the consequences of their behavior.
3. Some hear voices telling them to harm themselves.
4. Some do not know how to ask for help directly but kill themselves unintentionally (e.g., take too much pain medicine; cut wrists, etc.)

C. “Red flags” that warrant further exploration include the following:

1. Changes in the level of depression (more depressed or happier than usual), especially if he/she
   a. Has a specific plan for how to kill him/herself
   b. Has access to lethal means (such as weapons, pills, etc.)
   c. Feels worthless
   d. Talks about having done an unforgivable behavior
   e. Feels hopeless about the future
   f. Hears voices saying to harm him/herself
g. Begins to get his/her affairs in order (e.g., writes a will, gives things away, systematically contacts old friends or relatives)

h. Has experienced a recent significant loss (or perceived loss)
i. Lives with chronic medical illness and/or chronic pain

2. Has previously attempted suicide or has a history of being impulsive
3. Talks about killing him/herself (e.g., “Everyone would be better off without me”)
4. Makes suicidal gestures (takes too many pills, cuts wrists, etc.)
5. Talks about being indestructible or having supernatural powers during a manic or delusional state
6. Increases use of alcohol or other drugs. These substances may increase the level of depression AND may lower inhibitions, both of which are dangerous with suicidal people.

D. What to do if your family member is suicidal

**Discussion Questions:**

- What have you found to be helpful for yourself and for your loved one when he/she shares thoughts of suicide?

- How do you feel in these situations?

1. Talk about it. Asking about suicide will not put ideas in the person’s head and will not make the situation worse. Your family member may even feel relieved to be able to talk about it.

   Discussing suicidal ideation can be very important, as 50-70% of people who complete suicide communicate their intent in advance, usually to a family member (Adamec, 1996).

2. Offer emotional support by:

   a. Listening in a nonjudgmental, compassionate manner
   b. Empathizing with the person’s feelings (e.g., “It must be awful to feel that way”)
   c. Reminding the person of recent accomplishments
   d. Normalizing depression and thoughts of suicide
   e. Expressing your concern, care, and willingness to help

3. Ask if he/she has a plan about how to kill him/herself. If your family member describes a specific plan, then:

   a. Seek professional help immediately
b. Try to get him/her to promise that he/she will not act on these plans without first talking to you, a hotline, or a mental health professional.
c. Put away any objects that your family member may use to harm him/herself (guns, knives, pills, razors, etc.)

4. If the person is delusional (expressing false beliefs), seek professional help.

5. If you don’t know what to do, call a professional (e.g., suicide hotline, mental health professional, police)
   - **National SUICIDE Hotline**: 1-800-SUICIDE
   - **Veterans Affairs Suicide Hotline**: 1-800-273-TALK (8255)
     Suicide hotline in Oklahoma City: (405) 848-CARE

6. Sometimes suicide happens without warning, and nothing can prevent it from occurring.

7. Even with warning signs, there still may be nothing you can do.

8. Family members can benefit from discussing this issue with their loved ones when they are not actively suicidal. Together, the family and consumer can create a plan for coping with this inherently stressful situation if it arises again in the future.

9. Consider seeking professional help for yourself. Families often experience intense anxiety, worry and feelings of powerlessness when loved ones make suicidal threats.

VI. **Local treatment options for individuals living with depression and bipolar disorder**

**Example**: Oklahoma City VA Medical Center

A. Depression Management Class

- This eight-session class consists of three modules, and helps veterans to increase their pleasant activities, modify dysfunctional thought patterns, and improve their interpersonal skills.

B. Medications

- Primary care providers can prescribe many medications for depression and bipolar disorder. In addition, psychiatrists in the mental health units have special training in prescribing and monitoring psychiatric medications.
• Medications for depression and bipolar disorder are not habit forming, so consumers do not have to worry about becoming addicted to the drug.

• For major depression, antidepressants are quite effective. Most studies demonstrate at least a 50% decrease in symptoms for approximately 70% of people (Tamminga et al., 2002). A class of medications known as selective serotonin reuptake inhibitors (SSRIs), including medications such as Prozac, Zoloft, and Paxil, often have few side-effects and are helpful to many people living with depression.

• For bipolar disorder, many mood stabilizers are effective in helping consumers lead meaningful, productive lives and enjoy close relationships.
  o Lithium was the first medication introduced to treat bipolar disorder, and it is effective for many consumers.
  o Other medications (e.g., Depakote and Tegretol), which were originally created to prevent seizures, are also helpful in stabilizing moods.
  o Newer medications (e.g., anti-seizure medications like Neurontin and Topamax and anti-psychotic medications such as Clozaril, Zyprexa, Risperdal and Seroquel) are also being studied to assess their usefulness for people with bipolar disorder.
  o Sadly, medication compliance can be very challenging for these consumers because, although their moods may be less intense and cyclical, they miss the extreme enjoyable highs of mania. An excellent resource for consumers and families dealing with bipolar disorder (especially medication compliance) is The Bipolar Workbook: Tools for Controlling Your Mood Swings by Dr. Monica Ramirez Basco.

C. The REACH Project (Reaching out to Educate and Assist Caring, Healthy Families) – This 9-month family psychoeducation program provided by the Family Mental Health Program supports veterans and their family members in dealing with depression and bipolar disorder. 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. Day Treatment Center – The Day Treatment Center provides a structured, intensive program for veterans experiencing chronic mental illness (including depression).

E. Electroconvulsive Therapy (ECT)
  • Electroconvulsive Therapy (ECT), also known as shock treatment, is a safe and painless (yet rather controversial) treatment option for consumers with severe depression who do not improve with medications. The success rate of
ECT (80-90%) is higher than that with antidepressants (approximately 70%). ECT is administered by deliberately inducing a seizure, and the potential adverse effects of this procedure (e.g., confusion and memory loss) must be considered (Datto, 2000; Fink, 2001; United Kingdom ECT Review group, 2003).

- The consumer should discuss this option with his/her psychiatrist if interested in this treatment.

VII. Coping strategies for the family

A. Do’s

1. Acknowledge that clinical depression and bipolar disorder are legitimate illnesses. Learn about depression and its impact on the family.

**Good Books on Depression:**


**Good Books on Bipolar Disorder:**


**For Youth:**


Relevant Web Sites:

www.depression.org – comprehensive resources about depression

www.dbsalliance.org – Depression and Bipolar Disorder Alliance

www.depressionfallout.com – help for those dealing with a depressed loved one

www.familyaware.org – Families for Depression Awareness

2. Have realistic expectations (e.g., depression cannot go away overnight)…but also maintain hope.
   a. New antidepressants and treatment strategies are being studied and becoming available. Many people with depression are able to lead constructive lives.
   b. For example, the movie *Patch Adams*, starring Robin Williams, depicts a young man admitted to a psychiatric unit because of major depression and suicidal ideation, who later becomes a successful physician.

3. Be an active team member in the care of your loved one. Ask questions of doctors, nurses, psychologists, and other healthcare providers.
4. Offer emotional support, patience, and compassion. Encourage your loved one to exercise and do activities that he/she used to enjoy. Allow your loved ones to care for themselves as much as possible.
5. Stay in contact with your social support network.
6. Obtain professional help for yourself when needed.
7. Maintain good sleep habits, both for you and your loved one (e.g., go to bed and get up at the same time every day; reduce caffeine intake). Research has found that disrupted sleep patterns can trigger bouts of depression or mania (Frank et al., 2005), so regular sleep/wake times are very important.
8. Make healthy lifestyle choices (healthy diet; regular exercise; avoid use of alcohol).

B. Don’ts

1. Try not to take the depression personally – it’s not your fault! You cannot cure depression with love any more than you can cure cancer with love.
2. Don’t exclude the depressed person from family discussions or decisions.
3. Don’t try to do everything for the depressed person.
4. Don’t criticize the person for his/her depressed behavior or expect him/her to be able to simply “snap out of it.”
5. Don’t feel that you need to apologize for your loved one.
What Can I Do When My Family Member Is Depressed?

Common Symptoms of Depression

1. Feeling sad, blue, or down
2. Losing interest in previously enjoyed activities
3. Experiencing a change in appetite or weight
4. Having a change in sleep patterns
5. Feeling tired and slowed down OR feeling restless
6. Feeling worthless or guilty
7. Having trouble concentrating, thinking, or making decisions
8. Having thoughts of death or suicide

Common Symptoms of Bipolar Disorder

1. Feeling “high” or “on top of the world” or having an “overly” good mood
2. Needing less sleep than usual
3. Being more talkative than usual and/or pressured speech
4. Having racing thoughts and/or jumping quickly from one topic to another
5. Being easily distracted
6. Demonstrating excessive productivity and/or being more agitated than usual
7. Pursuing risky activities that can have bad consequences

Common Causes of Depression

1. Major life events (e.g., death of loved one, retirement)
2. Genetic factors
3. Imbalance in the level of chemicals in the brain
4. Medical illness
5. Use of certain medications (some anti-convulsants or thyroid hormones)
6. Excessive use of alcohol
**Suicide Warning Signs:** There are several “red flags” that you want to pay special attention to if a loved one is talking about suicide. One warning sign does NOT mean that the person is definitely going to harm him/herself; rather, these cues may prompt you to explore the issue further:

1. Changes in the level of depression (more depressed or happier than usual), especially if he/she:
   a. Has a specific plan for how to kill him/herself
   b. Begins to get his/her affairs in order (e.g., writes a will, gives things away, systematically contacts old friends or relatives)
   c. Feels worthless
   d. Talks about having done an unforgivable behavior
   e. Feels hopeless about the future
   f. Hears voices saying to harm him/herself

2. Talks about being indestructible or having supernatural powers during a manic or delusional state

3. Talks about killing him/herself (“Everyone would be better off without me”)

4. Makes suicidal gestures (takes too many pills, cuts wrists, etc.)

5. Increases use of alcohol or other drugs.

6. Has previously attempted suicide OR has a history of being impulsive

**What to do if your family member is suicidal**

1. Talk about it! Asking about suicide will not put ideas in his/her head and will not make the situation worse. Ask – then listen. You may want to discuss coping strategies at a time when your loved one is not actively suicidal.

2. Offer emotional support by expressing your concern, care, and willingness to help.

3. Ask if he/she has a plan about how to kill him/herself. If so, then:
   a. Seek professional help immediately.
   b. Try to get the person to promise that he/she will not act on these plans without first talking to you, a hotline, or mental health professional.
   c. Put away any objects that your family member may use to harm him/herself (guns, knives, pills, razors, etc.).

4. If the person is delusional, seek professional help.

5. If you don’t know what to do, call a professional (e.g., suicide hotline, mental health professional, police)

**SUICIDE HOTLINE: 1-800-SUICIDE**

**VETERANS AFFAIRS SUICIDE HOTLINE: 1-800-273-TALK (8255)**

**Oklahoma City Suicide Hotline:** (405) 848-CARE

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Support And Family Education:
Mental Health Facts for Families
Michelle D. Sherman, Ph.D.
Local Treatment Options for Veterans Living with Depression/Bipolar Disorder

1. Depression-management skills class
2. Anti-depressant medications
3. REACH Project – family psychoeducation
4. Day Treatment Center
5. Electroconvulsive therapy (ECT)

Coping Strategies for the Family

A. Do’s

1. Acknowledge that depression is a legitimate illness – which is different from just having a “down” day.
2. Learn about the illness of depression:

Good Books on Depression:


Good Books on Bipolar Disorder:


For Youth:


Support And Family Education:
Mental Health Facts for Families
Michelle D. Sherman, Ph.D.
Relevant Web Sites:

- **www.depression.org** – comprehensive resources about depression
- **www.dbsalliance.org** – Depression and Bipolar Disorder Alliance
- **www.depressionfallout.com** – help for those dealing with a depressed loved one
- **www.familyaware.org** – Families for Depression Awareness

3. Have realistic expectations…but maintain hope!
4. Be an active team member in the care of your loved one. Ask questions of doctors, nurses, psychologists, and other healthcare providers.
5. Offer emotional support, patience, and compassion. Encourage your loved one to exercise and do activities that he/she used to enjoy.
6. Stay in contact with your social support network.
7. Obtain professional help for yourself when needed.
8. Maintain good sleep habits, both for you and your loved one.
9. Maintain a healthy diet; engage in regular exercise; avoid use of alcohol.

B. Don’ts

1. Try not to take the depression personally – it’s not your fault! You cannot cure depression with love any more than you can cure cancer with love.
2. Don’t exclude the depressed person from family discussions or decisions.
3. Don’t try to do everything for the depressed person.
4. Don’t criticize the person for his/her depressed behavior.
5. Don’t feel that you need to apologize for your loved one.

Parts adapted from *When Someone You Love Has a Mental Illness* by R. Woolis (1992).
Session Three – PTSD and its Impact on the Family

I. Review of the diagnosis of PTSD

A. The diagnosis of post-traumatic stress disorder (PTSD) is made only when very specific criteria are met. One person who has been diagnosed with PTSD may look very different from another with the same disorder. The specific traumatic experience and the resultant impact on the individual and his/her loved ones are unique to each family. The diagnosis can be made only by a trained mental health professional (preferably one experienced in working with trauma survivors).

B. In psychiatry’s classification system, PTSD is termed an anxiety disorder – much like panic disorder, generalized anxiety disorder, and obsessive-compulsive disorder. Rather than outlining all the specific criteria for PTSD, we will review the major clusters of symptoms (DSM-IV, 1994).
C. First, the person experienced or witnessed an event that involved actual or threatened death or serious injury, and he/she felt very afraid or helpless. Traumatic events can include a wide variety of different experiences, including (but not limited to):

- Military combat
- Natural disasters (e.g., earthquakes, floods, hurricanes) for both victims and rescue workers
- Man-made disasters (e.g., 9/11/01, the Oklahoma City Bombing) for victims and rescue workers
- Sexual assault or other violent crimes
- Domestic violence
- School shootings
- Physical and/or sexual abuse
- Fleeing violence in one’s homeland (for immigrants)
- Torture

D. People may re-experience the event in a variety of ways:

1. May have distressing dreams or nightmares of the event.
2. May feel very uncomfortable when confronted with a reminder of the event (e.g., war movie).

E. People may avoid certain triggers or reminders of the trauma (e.g., conversations, places, and thoughts associated with the event).

1. For example, many veterans have strong reactions to the sound of helicopters, firework displays, thunderstorms, humid weather, and sand.
2. Veterans from the Global War on Terrorism often have difficulty driving on American soil, fearing the presence of improvised explosive devices (IEDs) or roadside bombs or the enemy nearby.

F. People often feel numb:

1. May feel emotionally distant from other people.
2. May engage in previously enjoyed activities less often.

G. People may experience increased arousal:

1. May be irritable and/or have angry outbursts
2. May experience insomnia (problems falling or staying asleep)
3. May be hypervigilant (e.g., the veteran may sit with his/her back to the wall in public places to be aware of all that is occurring around him/her)
4. May startle easily
II. Background information on PTSD

A. Community-based research has revealed a lifetime prevalence of PTSD in the United States today to be approximately 7-8%; it affects about 7.7 million American adults (Kessler, Chiu, Demler & Walters, 2005).

B. Although not formally labeled PTSD until recently, the symptoms have been recorded throughout history:
   1. Biblical accounts describe PTSD symptoms in Job, Joseph and David.
   2. Egyptian, Greek and Roman mythology refer to similar symptoms.
   3. Shakespeare describes nightmares and intrusive thoughts in Henry IV.
   4. In WWI the phenomenon was called "shell shock" or "soldier's heart."
   5. In WWII symptoms were called "combat neurosis" or "operational fatigue."
   6. The formal diagnosis of PTSD first emerged in 1980 in the American Psychological Association's Diagnostic and Statistical Manual of Mental Disorders (DSM-III)

C. Research with service members returning from the Global War on Terrorism indicates that 15-17% meet criteria for major depression, PTSD, or generalized anxiety disorder shortly after homecoming (Hoge et al., 2004).
   1. A prospective study of troops deployed to Iraq and Afghanistan found a three-fold increase in new-onset PTSD among military personnel who had been deployed and who had been exposed to combat, highlighting the importance of the actual exposure to combat (rather than simply deployment itself) in affecting subsequent mental health (Smith et al., 2008).
   2. A related study found that rates of PTSD symptoms, depression, and anger problems were two to five times higher 4 months after returning home (Bliese, Wright, Adler, Thomas & Hoge, 2007). Future research will examine the course of emotional problems among these service members over time. It is hoped that early identification and intervention may prevent the development of long-term problems for many of these men and women.

D. In general, most people who are exposed to a traumatic event experience some PTSD symptoms following the event, but the symptoms generally decrease over time and eventually disappear. Approximately 8% of men and 20% of women go on to develop PTSD. For both men and women, rape is the most common trigger of PTSD (National Center for PTSD).
E. Although symptoms of PTSD usually emerge within 3 months of the trauma \((DSM-IV)\), some individuals have a delayed onset. Some avoid facing the painful emotional residue from the trauma for many years, often using substance abuse or other addictive behaviors to distract themselves from the feelings. When the individual begins to exhibit symptoms of PTSD many years after the event, families may feel confused.

F. The course of PTSD is quite variable, as some symptoms may diminish rapidly while others may fluctuate in intensity throughout the individual's life. Approximately 30% of those who have PTSD develop a chronic form that persists throughout their lifetime (National Center for PTSD).

G. Several variables affect the likelihood that a trauma survivor will develop chronic PTSD, including (Brewin et al., 2000; Ozer, Best, Lipsey & Weiss, 2003)

1. Severity of the trauma
2. Duration of exposure
3. Extent of being actively involved (rather than a witness)
4. Dissociation at time of the trauma
5. Premorbid psychiatric functioning (including exposure to prior trauma)
6. Extent of social support

H. The Veterans Health Administration was the first institution to develop treatment programs for PTSD. Much-needed treatment programs began to emerge in the mid-1970s in response to the clinical need seen among Vietnam veterans.

I. The rates of comorbidity of PTSD and other psychiatric diagnoses are strikingly high (Brown, Campbell, Lehman, Grisham & Mancill, 2001; Kessler et al., 2005). If a person has PTSD, he/she is at greater risk for also having another diagnosis. In one large study of individuals with PTSD, 92% met criteria for another Axis I disorder (Brown et al., 2001); more specifically, the following disorders were also present at the following rates:

1. Major depression \(77\%\)
2. Generalized anxiety disorder \(38\%\)
3. Alcohol abuse/dependence \(31\%\)

Research specifically with veterans with PTSD has also documented quite high comorbidity rates (e.g., Orsillo et al., 1996). Regarding the Global War on Terrorism, one large study reported that 24-35% of soldiers admitted to using more alcohol than they meant to (Hoge et al., 2004).
III. Effects of combat veterans’ PTSD on relationships and families

- PTSD can result from a variety of different traumatic events; the intensity and duration of people’s reactions differ depending on many factors (e.g., nature of the trauma, extent of social support, level of premorbid functioning, participation in treatment, repertoire of coping skills).

- We will address the specific consequences of traumatic experiences in this section, with an emphasis on the sequelae of military combat. We will also review the potentially disruptive effects of these symptoms on relationships.

FACILITATOR NOTE: Veterans who have recently returned home from a war zone may experience an acute stress disorder or full-blown PTSD. Regardless of whether or not a mental health diagnosis is present, however, dealing with reintegration into one’s family, community, workplace, and civilian role can be challenging. Some specific challenges faced during this reintegration process – as well as ways mental health professionals can support families during this time – are outlined in Bowling & Sherman (in press) and may be useful supplementary material for this session if working with Global War on Terrorism veterans/families.

Discussion Questions:

- What is the toughest issue for you and your family in living with a veteran with PTSD?

- How do you cope?

A. Social anxiety

Discussion Question: How has the veteran’s social anxiety affected your family life?

1. Families may become isolated due to the social anxiety many veterans experience. As veterans often feel very uncomfortable in large groups and crowds, the family may be quite limited in its activities.

2. The veteran may pressure family members (directly and/or indirectly) to stay home with him/her, thereby narrowing family members’ social contacts and limiting their ability to obtain support. Family members often feel guilty for pursuing independent activities.
B. Angry outbursts

Discussion Questions:

- How have your loved one’s anger-management problems affected your relationship?
- Your family?
- Any concerns for the children?

1. Anger is often a “weapon” in the veteran’s arsenal of protection against painful feelings, memories, and thoughts. Anger can function as a barrier and further isolate him/her, as other people often pull away from the frightening hostility and rage.

2. Due to the veteran’s difficulty in managing his anger, the family may live in an atmosphere of constant chaos. This lack of emotional and sometimes physical safety can be damaging to the mental health and development of all family members.

3. Family members may be at greater risk for being exposed to verbal abuse (e.g., yelling, name calling) and physical abuse (e.g., throwing things, aggression). Both veterans with PTSD and their spouses/partners engage in higher levels of physical violence than do comparable family members when the veteran does not have PTSD (Jordan et al., 1992; Sherman et al., 2006). These repeated negative interactions damage the trust and cohesion within the family.

4. Children may acquire maladaptive patterns for the expression of anger. Although little research has been done on the children of trauma survivors, one survey revealed that the children of Vietnam veterans with PTSD are more apt to have behavioral problems than children of Vietnam veterans who do not have this disorder. Further, these veterans with PTSD report more parenting problems and poorer family adjustment than veterans without PTSD (Jordan et al., 1992).

5. Recent research has found that the strongest predictor of parent-child relationship problems was the parent’s emotional numbing. Hence, detachment, numbing and avoidance may directly affect the veteran’s ability to parent by decreasing his/her ability to engage the child in everyday activities (Ruscio, Weathers, King & King, 2002).
6. Spouses/partners are often torn between caring for the acting-out veteran and protecting the children from his angry outbursts.

7. Rage exhibited publicly may further alienate the family from its social network.

C. Emotional unavailability

**Discussion Questions:**

- How does it feel to live with a spouse/significant other with whom you do not feel connected?
- Or to have an emotionally distant relationship?
- How else do you get your needs for emotional intimacy met?

1. People with PTSD may be emotionally unavailable because they are preoccupied with managing mental stress. The emotional distance in the relationship may also stem from higher levels of fear of intimacy experienced by both veterans with PTSD and their partners (in comparison with couples in which the veteran does not have PTSD) (Riggs, Byrne, Weathers, & Litz, 1998).

2. Veterans are often reluctant or unwilling to share feelings with their spouses/partners and children. In fact, research has found that veterans with PTSD have difficulty with self-disclosure, emotional expression (Carroll, Rueger, Foy & Donahoe, 1985), and creating intimacy, likely in part due to the emotional numbing common to PTSD (Cook et al., 2004). Consequently, family members may feel rejected and lonely, and they may blame themselves for their loved one’s emotional distance.

3. The individual may struggle with experiencing and expressing positive emotions. He/she may be unavailable to his/her children and unable to meet their emotional needs.

D. Sleep disturbance

1. Given the difficulties many veterans with PTSD have with sleep (including insomnia, frequent wakeings, nightmares, etc.), many couples choose to sleep in separate beds (and rooms). This physical separation can parallel the emotional distance experienced in the relationship. Physical intimacy can also be adversely affected by this sleeping arrangement.
2. In addition, the veteran’s behavior during a nightmare can be very frightening for the spouse and family. In the midst of a nightmare or flashback, some people become physically aggressive, thinking that their spouse/partner is the enemy in a combat situation. Partners often report extreme terror and confusion about these experiences, as they do not understand the out-of-control behavior.

E. Difficulty managing family roles and responsibilities

Discussion Question: What challenges have you faced in negotiating family roles and responsibilities?

1. Given the veteran’s emotional instability, the spouse/partner may assume some traditionally male roles, such as primary breadwinner, head of the household, manager of family finances, and chief disciplinarian. Partners may feel overwhelmed by all the demands in their lives and may resent the veteran’s withdrawal from familial responsibilities.

2. Given that the partner has taken over many of the veteran’s responsibilities, he/she may be unable to pursue his/her own goals, which can breed further bitterness.

3. Children may acquire adult responsibilities at an earlier age, resulting in their maturing quickly and sometimes taking on the role of a “parentified child.”

4. Individuals with PTSD often have difficulty keeping their jobs, thereby creating financial duress on the family.

F. Given these potentially difficult family issues, the fact that Vietnam veterans with PTSD and their partners experience high levels of marital instability (Kessler, 2000), including greater levels of marital conflict (Riggs et al., 1998) and less marital satisfaction (Jordan et al., 1992) than do comparison families without PTSD, is not surprising.

G. Furthermore, for some families, the relationship problems among veterans with PTSD and partners are quite chronic (Cook et al., 2004). Veterans with PTSD are twice as likely to have been divorced (in comparison with veterans without PTSD) and almost three times as likely to have had multiple divorces (Jordan et al., 1992).
IV. Treatment options for PTSD

A. Participating in treatment for PTSD can be challenging, as people are invited to directly face memories and feelings that they may have avoided for many years. An individual is much more likely to succeed in treatment if the following prerequisites are in place:

1. He/she is not abusing alcohol or using any street drugs. As stated earlier, substance abuse is often an issue for people with PTSD. Survivors need to learn skills (such as through a substance abuse treatment program) to cope with strong emotions so that they can directly face the traumatic memories without numbing themselves with substances.

2. He/she has adequate coping skills (not suicidal or homicidal).

3. He/she has sufficient social support.

4. He/she has a safe living situation (not homeless or in an abusive environment).

B. In light of high operational tempo and the high rate of redeployment in the Global War on Terrorism, selection of the appropriate approach and proper timing for addressing PTSD issues is essential. For example, it would most likely be contraindicated to start an intensive exposure-based treatment for a traumatized veteran who would soon be returning to the war zone. Rather, enhancing coping skills and maximizing resiliency would likely be most effective for him/her at that time.

C. Although each person’s individualized treatment plan is unique, the following goals are often important aspects of therapy for individuals living with PTSD:

1. Examine and learn how to deal with strong feelings (such as anger, shame, depression, fear or guilt).

2. Learn how to cope with memories, reminders, reactions, and feelings without becoming overwhelmed or emotionally numb. Trauma memories usually do not go away entirely as a result of therapy but become less frequent and less intense.

3. Discover ways to relax (possibly including physical exercise).

4. Increase the frequency of pleasant activities.

5. Re-invest energy in positive relationships with family and/or friends.

6. Enhance sense of personal power and control in his/her environment.
D. Components of treatment for PTSD – Most treatment programs involve a comprehensive approach, including several modalities, including psychiatric medications, education for client and family, group therapy, cognitive behavioral therapy and writing exercises.

1. Psychiatric medications
   a. Choice of medication(s) depends on the specific symptoms and any co-morbid difficulties (e.g., depression, panic attacks)
   b. In general, medications can decrease the severity of the depression, anxiety and insomnia. However, there is no “cure” for PTSD.
   c. Medications may be prescribed by the primary care provider or psychiatrist.

2. Education for survivor and family about PTSD
   a. Education is very important, both for the survivor and the family and typically addresses the nature of PTSD (e.g., symptoms, course, triggers), communication skills, problem-solving skills, and anger management.
   b. Education can occur in a variety of modalities, such as couples/family therapy, psychoeducational programs, support groups, etc.

3. Group therapy
   a. Groups can decrease the sense of isolation that many trauma survivors experience. Group members can share their stories and support one another, providing assurance that they are not alone and that others can support them in the journey of recovery. Survivors can build trusting relationships in a safe group context, therein building their courage and confidence about interacting with others in their daily lives.
   b. Groups have a variety of formats, including process oriented, trauma oriented (e.g., telling one’s story), present-day focused (e.g., coping skills), and/or psychoeducational (e.g., anger management).

4. Cognitive/behavioral therapy
   a. Cognitive therapy involves inviting people to examine their thinking processes and replace irrational thoughts with more realistic thoughts. It has received strong research support. Cognitive restructuring is a cognitive therapy approach used with PTSD.
   b. Behavioral therapy involves inviting people to change their behaviors, which results in a shift in their mood/mental state. Behavioral interventions may include teaching relaxation techniques, imagery, and breathing techniques.
c. Anger-management training may involve both cognitive and behavioral skills.
d. Exposure-based therapy (e.g., flooding, desensitization) involves teaching the person coping/relaxation strategies and then supporting him/her in repeatedly “re-telling” the traumatic experience in great detail, so that the memory becomes less upsetting. Researchers have found specific exposure-based treatments such as “Prolonged Exposure” (Rothbaum, Meadows, Resick, & Foy, 2000) and “Cognitive Processing Therapy” (Resick, Nishith, Weaver, Astin & Feuer, 2002) to be very effective in decreasing symptoms of PTSD.

5. Writing exercises

a. A psychologist, James Pennebaker, Ph.D, at The University of Texas at Austin has performed extensive research over the past 15 years on the power of writing. He has studied many survivors of trauma and discovered interesting results about the healing potential of writing.
b. Pennebaker reports that people who write about traumatic events have many positive outcomes (e.g., fewer doctor appointments, decreased pain for arthritic patients, lower blood pressure, happier mood, increased lung capacity for asthmatics, etc.) (Pennebaker, 1997).
c. Writing may be associated with these positive outcomes because it helps people to
   • Feel a greater sense of control over their lives
   • Gain greater understanding of their feelings
   • Break the situation into smaller pieces
   • Pay more attention to their feelings

V. Opportunity for growth

A. Over the past decade, researchers and clinicians have begun to focus on the opportunities for growth that arise for some people who have experienced trauma. Drs. Richard Tedeschi and Lawrence Calhoun coined the term post-traumatic growth (PTG), and they have studied survivors of a wide range of traumatic events (sexual assault, disasters, car accidents, being taken hostage, combat, house fires, the Holocaust, etc.) (Tedeschi, Park & Calhoun, 1998).

B. Importantly, this growth is viewed as emerging from the struggle with coping with the trauma and its aftermath – not from the negative event itself. In addition, experiencing growth usually involves emotional suffering. Considering the possibility of growth does not negate the very real distress commonly associated with trauma.

C. In studying this construct, five factors/themes have emerged. Growth may occur in one or more of these domains:
1. Awareness of new possibilities in life
2. Closer relationships with others (sometimes including greater connection with others who have survived trauma)
3. Increased sense of personal strength
4. Greater appreciation of life
5. Deepening of spiritual life OR significant change in belief system – may include greater wisdom

Discussion Questions:

• Have you noticed any positive changes in your family member as he/she deals with the trauma? If so, what have you seen?

• Have you noticed any positive changes in your relationship since the trauma? If so, what have you seen?

• Have you shared this with your family member? (He/she would probably really like hearing it from you.)

VI. Tips for family members and friends on being in a relationship with someone who has PTSD

Distribute Handout F: PTSD and its Impact on the Family

A. Educate yourself about PTSD through reading, attending lectures, talking to others in similar situations, etc.

Books on PTSD:


Books for Youth:

For Young Children:


For Teenagers:


Relevant Web Sites:

- [www.ncptsd.org](http://www.ncptsd.org) – National Center for PTSD
- [www.patiencepress.com](http://www.patiencepress.com) – Site with examples of the *Post-Traumatic Gazette*
- [www.sidran.org](http://www.sidran.org) – Sidran Traumatic Stress Foundation
- [www.trauma-pages.com](http://www.trauma-pages.com) – David Baldwin’s Trauma Information Pages
- [www.adaa.org](http://www.adaa.org) – Anxiety Disorders Association of America
- [www.giftfromwithin.org](http://www.giftfromwithin.org) – Gift From Within: Resources for Survivors and Professionals

B. Do not push or force your loved one to talk about the details of his/her upsetting memories. Try to avoid feeling jealous if your loved one shares more with other survivors of similar traumas or with his/her therapist than with you. Rather, try to be grateful that your family member has a confidant with whom he/she feels comfortable.

C. Do not pressure your loved one to talk about what he/she is working on in therapy. Also, avoid trying to be his/her therapist.
D. Attempt to identify (with your loved one) and anticipate some of his/her triggers 
(e.g., helicopters, war movies, thunderstorms, violence).

E. Learn and anticipate some of his/her anniversary dates (e.g., Tet offensive, 
especially painful events)

Discussion Question: What have you noticed about your family 
member’s behavior around anniversary times?

F. Recognize that the social and/or emotional withdrawal may be due to his/her 
own issues and have nothing to do with you or your relationship. If you do not 
feel emotionally supported by your loved one, foster relationships with others 
(friends, family, etc.) from whom you can get that connection and support.

G. Do not tolerate abuse of any kind – financial, emotional, physical, or sexual. 
Individuals with PTSD sometimes try to justify their behavior (e.g., angry 
outbursts, destroying property, lying) and “blame” their wrongdoing on having 
this psychiatric disorder. People may try to rationalize their behavior by stating 
that they were “not themselves” or “not in control” or “in another world.” 
However, survivors should always be held responsible for their behavior.

H. Pay attention to your own needs.

I. Take any comments that your loved one makes about suicide very seriously, 
and seek professional help immediately.

J. Do not tell your loved one to just “forget about the past” or just “get over it.”

K. Explore the available treatment options in your community, and encourage your 
loved one to seek professional help. However, remember that confronting past 
hurts can be a very frightening and overwhelming experience. Therefore, 
respect that your loved one knows if/when he is ready to take this courageous 
step, and do not pressure him/her excessively.
VII. Tips veterans want their family members and friends to know

A. Veterans from the Oklahoma City VA Medical Center were asked to create “Top 10 Lists” of “What We’d Like our Family Members and Friends to Know About Living with PTSD.”

Distribute Handout G: (reproduced with permission of the veterans)

Discussion Question: How is this list similar and different from the above list of suggestions that professionals have made?

VIII. Local treatment options for veterans with symptoms of PTSD

Example: Oklahoma City VA Medical Center

A. PTSD Recovery Program – This 6-week intensive outpatient program focuses on unresolved feelings about combat experiences, as well as present-day coping skills. Specific groups address issues of anger management, communication skills, dealing with emotions, insomnia management, etc.

B. OIF/OEF Program – This program involves group and individual therapy to support veterans during the reintegration process. Composed of a psychiatrist, psychologist, social worker, and a patient liaison, this team works solely with veterans from the Global War on Terrorism. Because the VA system can initially be complex and confusing, these staff members help new veterans access a wide range of both physical and mental health treatment options.

C. Women/Men of Courage Programs – This 12-week, weekly, 90-minute psychotherapy group focuses on healing from a sexual trauma (experienced in childhood and/or in the military). Specific sessions address issues of safety, self-esteem, telling one’s story, and empowerment.

D. The 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 in dealing with PTSD. The program involves both single-family therapy and multi-family groups/psychoeducational classes. Sessions are held in the evenings to accommodate participants’ work schedules.

E. Some other VA facilities (including Little Rock, AK; Topeka, KS) offer time-limited inpatient programs for veterans with combat-related PTSD. Some also offer inpatient programs for veterans with sexual-assault-related PTSD.
PTSD and its Impact on the Family

The Diagnosis of Post-Traumatic Stress Disorder (PTSD)

A. The diagnosis of PTSD is made only when very specific criteria are met. The specific traumatic experience and the impact on the person and his/her loved ones are unique to each family. The diagnosis can be made only by a trained mental health professional.

B. First, the individual experienced or witnessed an event that involved actual or threatened death or serious injury, and he/she felt very afraid or helpless.

C. People may RE-EXPERIENCE the event in a variety of ways (e.g., distressing dreams).

D. People may AVOID certain reminders of the event.

E. People may report feeling NUMB.

F. People may experience INCREASED AROUSAL (e.g., anger, sleep problems).

Treatment Options for PTSD

A. Overall goals of therapy

1. Examine and learn how to deal with strong feelings (such as anger, shame, depression, fear or guilt).
2. Learn how to cope with memories, reminders, reactions, and feelings without becoming overwhelmed or emotionally numb. Trauma memories usually do not go away entirely as a result of therapy but become less frequent and less intense.
3. Discover ways to relax (possibly including exercise).
4. Increase pleasant activities.
5. Re-invest energy in positive relationships with family and/or friends.
6. Enhance sense of personal power and control in his/her environment.

B. Components of treatment

1. Psychiatric medications
2. Education for client and family about PTSD
3. Group therapy
4. Cognitive/behavioral therapy (e.g., Prolonged exposure; cognitive processing therapy)
5. Writing exercises
Tips for family members and friends on relationships with someone who has PTSD

A. Learn as much as you can about PTSD.

Books on PTSD:


Books for Youth:

For Young Children:


For Teenagers:

Relevant Web Sites:

www.ncptsd.org – National Center for PTSD

www.patiencepress.com – Site with examples of the Post-Traumatic Gazette

www.sidran.org – Sidran Traumatic Stress Foundation

www.trauma-pages.com – David Baldwin’s Trauma Information Pages

www.adaa.org – Anxiety Disorders Association of America

www.giftfromwithin.org – Gift From Within: Resources for Survivors and Professionals

B. Do not push or force your loved one to talk about the details of his/her upsetting memories. Try to avoid feeling jealous if your loved one shares more with other survivors of similar traumas or with his/her therapist than with you. Rather, try to be grateful that your family member has a confidant with whom he/she feels comfortable.

C. Do not pressure your loved one to talk about what he/she is working on in therapy. Also, avoid trying to be his/her therapist.

D. Attempt to identify (with your loved one) and anticipate some of his/her triggers (e.g., helicopters, war movies, thunderstorms, violence). Learn and anticipate some of his/her anniversary dates.

E. Recognize that your loved one’s social and/or emotional withdrawal may be due to his/her own issues and be unrelated to you or your relationship.

F. Do not tolerate abuse of any kind – financial, emotional, physical, or sexual. Individuals with PTSD sometimes try to justify their behavior (e.g., angry outbursts, destroying property, lying) and “blame” their wrongdoing on having this psychiatric disorder. People may try to rationalize their behavior by stating that they were “not themselves” or “not in control” or “in another world.” However, survivors should always be held responsible for their behavior.

G. Pay attention to your own needs.

H. Take any comments that your loved one makes about suicide very seriously and seek professional help immediately.

I. Do not tell your loved one to just “forget about the past” or just “get over it.”
J. Explore the available treatment options in your community, and encourage your loved one to seek professional help. However, respect that he/she knows if OR when he/she is ready to take this courageous step. Try to avoid nagging or excessive pressure.

**Local Treatment Options for Veterans with Symptoms of PTSD**

1. PTS Recovery Program
2. OIF/OEF Program
3. Men/Women of Courage sexual trauma groups
4. The REACH Project
5. Time-limited inpatient programs for veterans with PTSD (only at some sites)

What We’d Like our Family Members and Friends
To Know About Living with PTSD

Suggestions from Veterans who were Involved in Combat in the Vietnam War
Oklahoma City VA Medical Center
Spring, 2000
(Printed and shared with permission of the veterans in these groups)

1. GIVE ME SPACE when I need to be alone – don’t overwhelm me with questions. I’ll come and talk to you when I’m ready.

2. Get away from me if I am out of control, threatening or violent.

3. Be patient with me, especially when I’m irritable.

4. Don’t personalize my behavior when I explode or get quiet.

5. Learn and rehearse a time-out process.

6. Don’t patronize me or tell me what to do. Treat me with respect and include me in conversations and decision making.

7. Don’t pity me.

8. Don’t say, “I understand,” when there are some things that you cannot understand.

9. Realize that I have unpredictable highs and lows – good and bad days.

10. Anticipate my anniversary dates – recognize that these could be tough times.

11. I’d like to share my traumatic experiences with you, but I fear overwhelming you and losing you.

12. I want to be close to you and share my feelings, but I’m afraid to … and sometimes I don’t know how to express my emotions.

13. I also fear your judgment.

14. Know that I still love and care about you, even if I act like a jerk sometimes.

15. Don’t ask me to go to crowded or noisy places because I’m uncomfortable in those settings.
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).
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.
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.

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**

**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.
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:**

**Memoirs about Schizophrenia:**
*Tell Me I’m Here.* (1992). A. Deveson. (mother's experience of son with schizophrenia)
*The Quiet Room: A Journey out of the Torment of Madness.* (1994). L. Schiller & A. Bennett

**Relevant Web Sites:**
[www.schizophrenia.com](http://www.schizophrenia.com) – Schizophrenia Home Page
[www.schizophreniadiigest.com](http://www.schizophreniadiigest.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)

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
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).

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.
Schizophrenia and its Impact on the Family

The Diagnosis of Schizophrenia

The diagnosis of schizophrenia is made only when very specific criteria are met. Different combinations of symptoms distinguish various types of schizophrenia. For this reason, one individual with the disorder may appear very different from another person with the same disorder. The diagnosis can be made only by a trained mental health professional. Symptoms may include the following:

- DELUSIONS (false beliefs)
- HALLUCINATIONS (sensory experiences with no outside stimulation, such as hearing voices or seeing things others do not see)
- DISORGANIZED SPEECH (speech that is irrelevant or not on topic)
- DISORGANIZED BEHAVIOR (behavior that is inappropriate or an inability to take care of necessary daily activities)
- CATATONIC BEHAVIOR (staying in the same position for a long time)
- NEGATIVE SYMPTOMS (lack of interest, low motivation, lack of emotional expression)

Tips on Being in a Relationship with Someone Who Has Schizophrenia

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

Good Books on Schizophrenia:


Memoirs about Schizophrenia:

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

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


Relevant Web Sites:

www.schizophrenia.com – Schizophrenia Home Page
www.schizophreniadigest.com – magazine focusing on providing inspiration and information about mental illness

2. If you suspect that your loved one is experiencing hallucinations (appearing distracted, talking to self, laughing suddenly and for no obvious reason):

a. Ask the person about his/her current experience and what will help him/her to feel safe and in control.

b. Suggest the possibility that the experience is a symptom, without casually dismissing it.

c. Calmly yet firmly remind your loved one of any necessary limits (e.g., “You need to stop screaming.”).

3. When your loved one makes delusional statements:

a. Avoid discussing the details of these comments in depth. Do not try to convince him/her that the delusion is wrong or not real.

b. If your loved one is agitated, listen calmly and respectfully. Respond by focusing your attention primarily on reality-based remarks.

4. Respond to disorganized speech by communicating calmly and directly:

a. Don’t worry about being unable to understand the content of the speech; rather, focus on conveying your respect for the person.

5. Recognize that your loved one’s symptoms have nothing to do with you or your relationship.

Support And Family Education:
Mental Health Facts for Families
Michelle D. Sherman, Ph.D.
6. 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.

7. Pay attention to warning signs of a potential relapse, including discontinuing medications, insomnia, increased social withdrawal, auditory/visual hallucinations, worsening in personal hygiene, etc.

8. Communicate honestly and regularly with your loved one’s providers.

9. Encourage your loved one to participate fully in his/her treatment by taking medications regularly and attending various therapies.

10. Choose your battles! Practice tolerance for annoying behaviors.

11. Do not neglect your own needs, as doing so may build resentment toward your loved one.

12. Take any comments that your loved one makes about suicide or harming others very seriously, and seek professional help immediately.

13. Notice and praise any positive behaviors (taking medicine regularly, staying calm when experiencing upsetting hallucinations or delusions, etc.) in your loved one often.

Treatment Options for Individuals with Schizophrenia

- Medication management (pills and/or regular injections)
- Family psychoeducation/education
- Compensated work therapy/supervised job coaching
- Assertive Community Treatment (ACT) teams/Mental Health Intensive Case Management (MHICM) program
- Self-help groups
- Day Treatment Center
- High-Functioning Schizophrenia Group


*When Someone You Love Has a Mental Illness* by R. Woolis (1992)
Session Five - Communication Tips for Family Members

Materials Needed:
Handout I: Communicating With Your Loved One
Handout J: Practicing I Messages

Brochures on local treatment options for individuals who wish to improve their communication skills

I. Reasons why communication skills are important

A. Improving communication skills can reduce the frustration and stress in the family and facilitate healthy interactions. (When families that have a loved one living with mental illness are asked about their concerns, they often report significant worry about the high level of stress in the household and the nature of the relationships within the family unit [Pollio, North & Foster, 1998]).

B. Learning to better understand the ways your loved one thinks and processes information can improve communication.

C. Being able to communicate and genuinely trying to understand each other’s feelings can be very meaningful: “The most healing gift you can give to someone in pain is the awareness that you are honestly trying to understand what they are going through, even if you get it wrong.” (Hudson, 1999, p. 37)

D. Research has revealed that families who learn and use good communication skills and solve problems well as a family can significantly reduce the likelihood that their loved one will be re-admitted to the hospital – and reduce the length of stay if he/she does need to go into the hospital (Dyck et al., 2002; McFarlane, 2002).
II. Understanding mental illness and its impact on communication

Individuals with a mental illness often process information differently. Remembering these points in your communication with them can be quite helpful: (parts adapted from Woolis, 1992)

A. Issue #1: Sometimes individuals withdraw (physically and/or emotionally) because they feel over-stimulated. People with a mental illness may have a limited capacity for commotion, so they can feel overwhelmed easily and quickly.

Tip for Families: Avoid taking the withdrawal personally, and remain available if your loved one wants to talk later. You may wish to initiate a discussion about the withdrawal pattern at a later time.

B. Issue #2: Social situations can be very stressful for people with a mental illness (especially for individuals with schizophrenia, depression, PTSD and other anxiety disorders), as groups or crowds can be threatening and anxiety provoking.

Tip for Families: Your loved one may feel more comfortable having only one or a few visitors at a time. You can also limit the length or frequency of large-group activities.

C. Issue #3: Individuals with a mental illness may have an impaired ability to express emotions. Consequently, they may appear detached, cold or emotionally aloof.

Tip for Families: You will probably feel better if you can understand this emotional distance as part of the illness rather than as a reflection of a relationship problem or some wrongdoing on your loved one’s part.

D. Issue #4: On the other hand, some people display intense, rapidly escalating emotions. For example, individuals with PTSD often have angry outbursts, which can be frightening for family members and other observers.

Tip for Families: Although your loved one should be held responsible for his/her behavior and face appropriate consequences, you can recognize the heightened emotionality as a symptom of the illness.

E. Issue #5: People with schizophrenia often feel bombarded with information, as thoughts and feelings seem to come from both the inside (often as auditory hallucinations or “voices”) as well as the outside world. Therefore, these individuals may struggle to sort out the incoming information and may feel confused. In communicating with them, you may notice that they seem
distracted or withdrawn (in a “world of their own”); they may change the topic for no apparent reason; and they may be unable to stick to one subject at a time.

Tip for Families: Communication is most effective when it is straightforward, brief, and includes repetition of key points. Further, avoid arguing about the validity or existence of your loved one’s delusional beliefs or hallucinations, as the debate will be ineffective and will only heighten the tension.

III. Specific issues in communicating with your loved one

Families are often entrenched in old, familiar patterns of communication. Some habits may be effective, whereas others may not work any longer.

Discussion Question: What are some important issues to remember in effective communication?

Distribute Handout I: Communicating With Your Loved One

A. Do’s

1. “Two-Sentence Rule” – Keep your communication simple, clear and brief.

2. Ask only one question at a time.

3. Stick to the current issue rather than bringing up “old issues.”

4. Stay calm. Your loved one may become even more uncomfortable and withdrawn if you express intense emotions.

5. Minimize other distractions by turning off the television and radio.

6. Pay attention to nonverbal behavior – both the message that you are sending with your body language and that of your family member. Sometimes people with a mental illness struggle to identify and express their needs and feelings; consequently, focusing on their behavior and emotional state rather than just their words can be important.

7. Help your loved one identify his/her feelings by suggesting several choices (e.g., “Are you feeling angry, sad or worried right now?”).

8. Acknowledge what you have heard him/her express. Show empathy or caring for his/her feelings. You may wish to normalize that emotion and share a similar experience that you have had in the past.
9. Decide together on a regular time for communication. Even if you are together most of the time, families benefit from having a set time to routinely talk about delicate matters. Choosing a low-stress time when both of you are apt to feel at your best is important.

B. Don’ts

1. Don’t try to argue your loved one out of delusional or false beliefs. Your efforts to convince him/her that the belief is wrong will only increase the stress in the situation and will probably not change his/her views.

2. Avoid giving advice unless asked – or if the person cannot make the decision on his/her own. Rather, make decisions together whenever possible.

3. Avoid interrupting each other.

4. Don’t talk down to each other (e.g., “You are acting like a child”).

5. Avoid name calling.

6. Don’t generalize (“always” or “never”). Focus on the specific behavior rather than the individual.

7. Don’t yell or shout.

8. Don’t personalize the family member’s behavior. Recognize that the symptom may be part of the mental illness and may have nothing to do with you.

IV. Specific skill: *I* statement

A. One specific tool for making a direct communication is called the *I* statement. This skill requires the speaker to take responsibility for his/her feelings and desires.

*Write on Board:* When you __________, I feel ________________.

B. Examples

1. When you burst in my room without knocking, I feel…
2. When you threaten me, I feel…
3. When you sleep all day, I feel…
C. Advantages of using the *I* statement

1. These messages get the listener’s attention. Individuals often become overly self-involved and may be unaware of other family members’ feelings.
2. These messages are non-blaming, so they minimize defensiveness.
3. These messages force the speaker to identify, express, and take responsibility for his/her own feelings.

D. Various uses of the *I* statement

1. To make a request
   a. **Example:** “I want you to go to the day treatment program. When you have a structured schedule, I feel relieved and proud of you.”

   b. People feel motivated to do what you ask when you express pride in them.

2. To give praise
   a. **Example:** “When you clean up the house, I feel happy.”

   b. Praise strengthens the relationship and increases the likelihood that the individual will do the behavior again in the future.

3. To express negative feelings
   a. **Example:** “When you refuse to take your medications, I feel worried and frustrated.”

   b. Family members often feel quite frustrated with their loved ones, and they may express their irritation in destructive ways (e.g., “You aren’t even trying to help yourself!” or “You’re just going to end up back in the hospital again if you keep this up!”).

   c. The *I* message redirects the focus back to the family member’s concern about the person’s behavior.

4. To ask the individual to change his/her behavior
   a. You need to include three parts when giving this form of feedback:
      1. Exactly what the person did
      2. How you feel about the behavior
      3. How you would like him/her to behave in the future
b. **Example:** “When you left the kitchen a mess last night, I felt irritated. I would feel happy if you would put the dishes away and wipe off the counter.”

V. **Specific skill: Softened start-up - How to approach your family member**

Psychologist John Gottman, Ph.D, describes a couples therapy principle called the “softened start-up.” Although this approach was originally developed for couples, it can be easily adapted to help family members talk to their loved ones.

Softened start-up involves approaching your loved one in a non-confrontational, non-critical manner. You may express dissatisfaction or complain, but your tone of voice and attitude are gentle. Research from Dr. Gottman’s lab has found that discussions that start softly are much more likely to end softly and have a positive outcome (Gottman, 2000).

Dr. Gottman describes the softened start-up as including the following:

1. **Expressing complaint directly (but without blaming)**
   - “I feel concerned that you spend so much time on the couch watching television. I would really like you to go back to the day treatment program at the hospital.”
   rather than
   - “You just lie around all day and do nothing. Why don’t you ever offer to help out around here?”

2. **Using I statements (as discussed above)**
   - “I am worried about your drinking beer when you go out with your friends on the weekends”
   rather than
   - “You never think about anyone but yourself! You know your medications don’t work when you drink alcohol.”

3. **Describing the event rather than evaluating or judging it**
   - “I notice you haven’t been taking your medications this weekend”
   rather than
4. Using polite language (please) and being appreciative

- “I feel so happy and proud of you when you pitch in with household chores. Thanks a lot for doing the laundry. Would you please put the white load in the dryer?”

- “Didn’t you hear the washing machine buzzer? Put the clothes in the dryer.”

VI. Role play

Use of the I statement and having a “soft” start-up are truly easier said than done. You can benefit from practicing these skills in various situations. Family members have reported success in using this skill in various relationships (with friends, children, co-workers, other family members, etc.).

*Distribute Handout J: Practicing I Messages. Have participants get a partner and complete the worksheet together.*

1. Return to the large group, and discuss participants’ reactions.

2. Encourage participants to share this activity with other family members and to practice these skills.

VII. Recommended bibliotherapy on communication skills


Communicating With Your Loved One

**DO’s**

1. “Two-Sentence Rule.” Keep your communication simple, clear and brief.
2. Ask only ONE question at a time.
3. Stick to the current issue rather than bringing up “old issues.”
4. Stay calm.
5. Minimize other distractions by turning off the television and radio.
6. Pay attention to nonverbal behavior – both the message that you are sending with your body language and that of your family member.
7. Help your loved one identify his/her feelings by suggesting several choices (e.g., Are you feeling angry, sad or worried right now?)
8. Show empathy or caring for his/her feelings.
9. Acknowledge what you have heard him/her express. You may wish to normalize that emotion and share a similar experience that you have had in the past.
10. Decide together on a regular time for communication. Choosing a low-stress time when both of you are apt to feel at your best is important.

**DON’TS**

1. Don’t try to argue your loved one out of delusional or false beliefs.
2. Avoid giving advice unless asked – or if the person cannot make the decision on his/her own.
3. Avoid interrupting each other.
4. Don’t talk down to each other (e.g., “You are acting like a child”).
5. Avoid name calling.
6. Don’t generalize (“always” or “never”).
7. Don’t yell or shout.
8. Don’t personalize the family member’s behavior. Recognize that the symptom may be part of the mental illness and may have nothing to do with you.

Good Books on Communication Skills:


*The Seven Principles for Making Marriage Work.* (1999). Gottman and Silver

Support And Family Education:

Mental Health Facts for Families
Michelle D. Sherman, Ph.D.
Practicing I Messages

FORMAT OF I MESSAGE =

WHEN YOU ____________, I FEEL ____________.

The purpose is to tell someone how you feel about his/her behavior without degrading, accusing, or arousing anger in the other person.

Example: When YOU give me a big hug, I FEEL happy, loved, and close to you.

1. When you say something nice to me, I feel ____________________________.

2. When you don't come home on time, I feel ____________________________.

3. When you are rude to me in front of your friends, I feel ____________________.

4. When I was sick and you fixed me dinner, I felt ____________________________.

5. When you clam up and won't talk, I feel ________________________________.

6. When you listen to me when I'm upset, I feel ____________________________.

7. When I'm talking to you and you turn on the TV, I feel ____________________.

8. When you yell at me, I feel ________________________________.

9. When you talk about our special memories, I feel ________________________.

10. When you make dinner for me, I feel ________________________________.

11. When you criticize me, I feel ________________________________.

12. When you keep the house clean, I feel ________________________________.
Materials Needed:
   Handout K: Coping with Mental Illness

I. Introduction

Maintaining a balance between taking care of your loved one and setting boundaries to take care of yourself can be very challenging. You may feel guilty for setting limits, so this skill is very important to discuss and practice.

Listen to this description of a situation between a married couple, Joe and Helen. Think about how each person may be thinking and feeling in this scenario and what each could do.

**Read the following scenario aloud:**

“One Sunday Joe wanted to take the hour-long drive to his daughter’s home to visit her and her family. He was particularly eager to see his grandchildren, who had called the previous day, begging them both to visit. Joe knew that Helen was once again deeply depressed. Whenever she was that down, she wanted nothing more than to stay in the bedroom watching TV. Experience had taught them both that if Helen forced herself to go out when she was depressed, she felt even more engulfed in the depression. When she felt this way, she did not want to be around her daughter, her son-in-law, or her grandchildren. Helen and Joe both knew that if she agreed to go, she would feel more miserable and useless than she already did.

Joe had a dilemma about what to do.” (Rosen & Amador, 1996, p. 134)
Depending on the number of participants, break into groups of three or four people. Write the following discussion questions on the board, and allow the groups 10 minutes to discuss these issues. Then, return to the large group and discuss the groups’ responses.

**Discussion Questions:**

- What might Joe have been thinking in this scenario?
  a. I really want to visit my grandchildren today, but I just cannot leave Helen like this. I know Helen wants me to go, but I’d feel so guilty leaving her alone.
  b. I sure wish Helen would go, as I think she’d feel better if she saw the grandchildren.
  c. I worry that I’ll start to feel depressed if I don’t go see my family. Then I won’t be able to support Helen.

- How might Joe have been feeling?
  Ambivalent, torn, confused, frustrated, disappointed, guilty, worried, resentful, etc.

- What might Helen have been thinking?
  a. I don’t want to disappoint Joe and the children, but I just cannot go today.
  b. I’m sick and tired of feeling so depressed. I sure wish I felt better.
  c. I don’t want to be a burden for Joe, and I know he really needs to see the grandkids.

- How might Helen have been feeling?
  Afraid of being alone, lonely, depressed, isolated; angry at being left, etc.

- What are Joe’s options in this situation?
  a. Stay home and resent Helen.
  b. Stay home and take pride in his decision to support his wife.
  c. Go, but call Helen several times to check in.
  d. Go and try to forget about Helen.
  e. Go, but feel guilty and struggle to enjoy the visit.
  f. Invite the daughter’s family to come to their house.
  g. Discuss with Helen his desire to see the grandchildren and problem-solve as a couple.

- Have you faced similar situations? How have you dealt with them?
II. Remembering your own needs

**Discussion Question:** How can paying attention to your own needs be difficult?

A. You may be uncomfortable expressing your needs.
   1. You may feel awkward or uncomfortable asking for what you want.
   2. In stating your need, you become vulnerable to the possibility that the listener may say no.

B. You may fear being selfish.
   1. You may be uncertain as to whether your request is “reasonable.” You may convince yourself that your needs are somehow less important than those of your family member.
   2. You may be tempted to give all your energy (resources, time, money, etc.) to the family member. In so doing, you can lose yourself, and that strategy will eventually backfire. You may even forget that you have personal needs that you are neglecting.

C. Guilt can drive you to ignore your own needs.
   1. The consequences of ignoring your own needs over time usually are anger and resentment. These emotions can be expressed in one or more of the following manners:
      a. May be directly expressed to your loved one.
      b. May be displaced onto the children, co-workers, other family members, the family dog, etc.
      c. May be passive aggressively expressed to the family member (e.g., coming home late with no explanation; making meals that you know he/she dislikes).
      d. May be turned inward on yourself, which can result in depression or self-destructive behavior.
III. **Tips on striking a healthy balance between caring for your loved one and paying attention to your own needs** (parts adapted from Rosen & Amador, 1996):

**Discussion Question:**

Virginia Morris (1996) urges people caring for a loved one to get rid of the little voice in their heads that says, “I can do it all. I am responsible for everything…and whatever I do, it’s not enough” (p. 20).

- Can you relate to this sentiment?
- How can families change this “little voice” into a more reasonable, healthy inner dialogue and approach?

A. In addition to helping your loved one, remember that your needs are equally important. Strike a balance as often as possible.

1. If you immediately think, “I’m just being selfish,” you miss the opportunity to find a way of getting your need met.
2. It’s not always bad to be selfish! Your own needs are just as important as those of your loved one. Take time to “refuel.”
3. Give yourself time to think it out.

B. Talk about your needs constructively.

1. Ask for your loved one’s help in getting what you want.
2. Weigh your needs carefully against those of your loved one. Work together to discuss all issues openly.

C. Look for ways your family member can help you. All people need opportunities to be useful and helpful. Doing even small tasks for another person can enhance self-esteem and strengthen relationships.

D. Don’t be afraid to disappoint your loved one occasionally.

1. No one can meet another’s needs all the time or perfectly.
2. Your loved one is usually strong enough to bounce back!

E. Continue to devote time and energy to your other relationships. The fact that other family members or friends are well makes them no less deserving and needy of your time and energy.
IV. **Negotiating compromises**

A. Living with family members can be difficult, and compromise is often important for the household to function well. The situation can be even more difficult when your loved one has a mental illness. Certain behaviors may be especially difficult to negotiate (e.g., poor hygiene, excessive use of nicotine, lack of involvement in household chores, excessive sleeping).

B. Family members often face the challenge of differentiating between an annoyance and a real problem. Families can become consumed with the mundane annoyances of daily living (e.g., leaving clothes on the floor), leaving less energy for more significant problems.

C. If you decide that an issue warrants a frank discussion, the following tips can be helpful:

1. Focus on one specific behavior at a time.
2. Prioritize what is most important to you at that time.
3. Ask for more of what you’d like rather than criticizing the person’s behavior.

4. **Example:**

   Let’s say that your husband showers only once per week, smokes two packs of cigarettes per day, sleeps until noon every day, and recently discontinued his psychiatric medications. You haven’t said anything for a long time. Finally one day you are very frustrated and decide that things have to change.

   You angrily tell him that he has to get up every day at 8am and take a shower. He must cut back to three cigarettes per day, re-start his medications, and get a part-time job to fill up all his spare time.

   What would be the outcome? He would probably feel overwhelmed and angry and probably wouldn’t do what you asked. He would likely feel pressured and badly about himself.

   What could you do instead?

   - You could sort through your own frustrations, possibly with the help of a trusted friend or support group. In doing so, you would likely decide that the medication issue is most important at this time. You might still feel irritated about the other behaviors but could choose to focus your energy on the more serious issue.
• You could sit down with your family member at a calm time and discuss your concerns about his/her decision to discontinue medications. You could seek to understand the reasons for this choice.

• Together you could explore options for dealing with this situation, perhaps in coordination with his psychiatrist. All people respond better to requests for change when they feel included in the decision-making process (rather than being told what to do).

V. Financial issues

A. Managing finances can be quite stressful for families. Consumers may have difficulty obtaining income to which they are entitled because of their disability. Consumers may also struggle with financial management, which can create significant distress for the family.

B. In general, consumers should retain as much control over their finances and decision-making as they are able to manage competently.

C. Social workers are important contacts for dealing with financial matters. Several options exist, including court-appointed conservators, payees, legal guardians, power of attorney (etc.) that allow family members or other court-appointed individuals to obtain control of decision making of the estate, health care, and/or finances.

Provide local contacts for assistance with financial issues (e.g., social workers).

VI. Where to put your energy

There are many things that you as family members can do – but there are also things that you cannot do. Unfortunately, some people spend a great deal of energy trying to change things that cannot be changed.

Distribute and discuss Handout K: Coping with Mental Illness, originally written by Rex Dickens of NAMI.
VII. Personal examples

Discussion Questions:

- Would you like to share personal examples of times when
  - You set a limit that had a positive outcome?
  - You set a boundary but struggled to enforce it consistently?
  - You set a limit and it was difficult?
- During difficult times, how did you get the strength and support to set the limit?
- Are you currently facing any situations with your family member that you’d like input from other group members on how to handle?
Coping with Mental Illness

What Family Members Can and Cannot Do

By Rex Dickens of NAMI (revised by Michelle D. Sherman, Ph.D.)

What Family Members Can Do:

1. Talk about your feelings, and encourage other family members to do the same.
2. Talk to others who are also dealing with mental illness in the family (e.g., SAFE Program).
3. Learn about mental illness.
4. Choose your battles carefully. Prioritize what is most important to you.
5. Pay attention to your own needs.
6. Remember that all family members are affected and that “well” family members also need your attention. Avoid making the individual with mental illness the focus of all of the family’s attention.
7. Strive to respect the coping strategies different family members may adopt.
8. Seek to improve the mental health system so that treatment options are available.
9. Acknowledge your family member’s admirable courage in coping with the illness.
10. Separate the person from the illness. Love the person even if you hate the disorder.

What Family Members Cannot Do:

1. Make the mental illness go away.
2. Meet your loved one’s needs all the time.
3. Lessen the impact of the illness by not talking about it.
4. Grieve (mourn) for others. Grieving involves many steps, including denial, sadness, anger, and acceptance. Everyone must complete this process in his/her own way and at his/her own pace.
5. Take away peer and societal stigma and judgments.
6. Make the family member seek help (or take medications) if he/she is in denial (unless he/she is dangerous).
Session Seven -
Problem-Solving Skills for Families

Materials Needed:
Handout L: Problem-Solving Skills

As the popular bumper sticker says, “Stuff happens.” Problems are an inevitable part of life, and learning how to cope effectively with problems is important. Confronting problems can be challenging, especially if difficulties accumulate, involve numerous people, and/or involve a sense of helplessness. We often don’t deal with problems effectively when we’re overwhelmed by strong emotions.

Problem solving can be especially challenging for families coping with mental illness. When family members attempt to address problems with the consumer, frustration and challenges may arise. Family members may be repeatedly disappointed at their loved one’s past poor decisions and their consequences. Families may resent their sense of burden that they “have to” make all the decisions, only to feel angry when their loved ones fail to comply.

Further, individuals with mental illness may face special challenges dealing with problems, such as heightened emotionality, irrational thinking, impaired judgment, impulsivity, and distorted perceptions. Consumers may resent their perception (or the reality) that they have little or no input in important decisions.

This session will review several problem-solving styles, strategies for effective problem solving, and a specific process that can be helpful in addressing problems. You will have an opportunity to practice the process with a real-life problem.
I. Common problems for families dealing with mental illness

**Discussion Question:** What are some challenges that your family faces?

Possible answers may include:
- Disagreements among family members
- Financial difficulties
- Medication compliance
- Drug and alcohol use/abuse
- Lack of participation in family activities (e.g., including doing household chores, going to church)
- Failure to follow household rules (e.g., issues about smoking)
- Coping with potentially stressful life events (e.g. family celebrations, moving, deaths)
- Threats of danger (e.g., suicidal comments/behavior; threats and/or acts of violence)
- Coping with the mental health system (e.g. changes of provider, inpatient admissions, insurance)
- Others?

II. Styles of problem solving

**Discussion Questions:**

- Do you know of someone who seems to be able to cope with whatever life sends his or her way? What does he/she do?
- What are some ways that we cope with problems in our lives? What are the benefits? And the costs?
- Are you open to learning new ways of coping with problems?

A. Theorists have described several different styles of problem solving. We will now describe each style (as described by Mueser & Gingerich, 1994), as well as potential benefits and consequences of each style. As the styles are described, think about which style best describes your approach to problems. You may also recognize other family members’/friends’ styles. Understanding and respecting different approaches to solving problems is helpful in understanding others.

1. Avoidant style: “If I don’t see the problem, it’s not there.”

   - **Description:** This style may reflect denial of the existence and/or severity of the problem, or a decision to avoid dealing with the problem.
   - **Potential benefit:** With this style, you don’t have to admit to yourself or anyone else that a problem exists.
• **Potential consequences:** Avoiding problems usually makes situations worsen over time. In addition, strategies that might have been effective if you had confronted the situation earlier may no longer be feasible.

2. Discouraged style: “I can’t do anything about it anyway, so why even try? It won’t make any difference.”

• **Description:** Because families often feel powerless and discouraged by previously failed attempts at solving problems, this style is understandable. Inertia can take hold in a family, barring efforts at change.

• **Potential benefits:** This approach allows for passivity, and others will not hold you accountable for doing anything.

• **Potential consequences:** This attitude increases disappointment and the sense that there isn’t anything the family can do to deal with the problem. Potentially helpful solutions may be missed.

3. Take-over style: “People should do what I think is best; I’m in charge.”

• **Description:** Family members may attempt to take control of various situations, believing that the family system would work well if others simply abided by their decisions.

• **Potential benefits:** Family member feels productive by taking action and making changes for the family. Changes occur.

• **Potential consequences:** This style places full responsibility for problems on one individual. Although the “take-over” approach can seem initially empowering, it can also involve a sense of burden. Further, the decision-maker misses potentially constructive solutions from other family members.

4. Talking style: “If I talk about the problem long enough, it will get solved.”

• **Description:** This style emphasizes talking about the problem, which can ease distress.

• **Potential benefits:** Family members are talking with one another and specifically addressing the problem.

• **Potential consequences:** Simply talking about the problem doesn’t actually do anything towards solving the issue (unless you’re talking about solutions). This approach can be a form of procrastination.
5. Active style: “If there is a problem, there must be a solution.”

- **Description:** This approach involves directly assessing the problem, exploring potential solutions, and taking concrete action. This has been found to be the most effective problem-solving style.

- **People who use this approach commonly**
  
  a. See problems as inevitable, and don’t blame themselves for their occurrence.
  b. See problems as challenges to be confronted (rather than threats to be avoided).
  c. Recognize that attempting a solution (even if it doesn’t work) is better than never trying to do anything about the problem.
  d. Believe that there is a solution to every problem, or at least something that can be done to improve the situation.
  e. Believe in their ability to find a solution.
  f. Recognize that solving most problems takes time and effort.

- **Potential benefits:** All family members are involved in the problem-solving process; decisions made using this approach are more likely to be implemented and effective.

### III. Tips for effective problem solving

Before outlining a specific strategy for solving problems, we will review a few general guidelines on increasing the likelihood of having a successful outcome. [parts adapted from Mueser & Gingerich, 1994; Woolis, 1992]

A. Approach the problem with an upbeat, optimistic outlook.

1. Research has found that a positive frame of mind fosters creativity and effective problem solving.
2. A positive attitude can make family interactions about the problem go more smoothly.
3. Timing is important. Select a time to address the problem when you and your family members are feeling calm and able to focus. You may choose to ask your loved one, “Is this a good time to talk?” Or you may schedule a regular time (e.g., after dinner on Sundays) to discuss family issues.
4. Rather than dwelling on how disruptive the problem has been historically, try to focus on how the problem can change for the future.
B. Respect each person’s perspective.

1. Try to consult everyone involved in the problem or situation.
2. Try to see the problem from each person’s point of view. Otherwise, you’re likely to choose solutions that others do not feel good about and are therefore not willing to use to solve the problem.

C. Avoid blaming.

1. Often, people try to determine the cause of the problem, thinking that this is where the solution lies. It is important to remember that searching for a cause is not the same as defining and implementing a solution.
2. Blaming usually impedes problem-solving because looking for a cause takes the focus away from looking for solutions.
3. Blaming also tends to make people feel attacked, which can lead to a denial of the problem or refusal to help in solving it.

D. Compromise if necessary.

1. Be flexible when considering solutions. This ensures consideration of many viewpoints and allows others to feel that their input is important.
2. If everyone is encouraged to contribute during the brainstorming, he/she will be much more likely to participate when it is time to implement the solution.

E. Be flexible and patient, especially when first learning these skills.

1. Remember that there rarely are obvious “right” or “wrong” answers. You are striving to find a solution that might work well for this particular problem at this time.
2. Reassure yourself by remembering that ALL families disagree about issues and have different opinions. Your challenge is to work together to deal with the problem. The process of confronting and solving problems as a team has the potential to bring your family closer together.
IV. Specific steps in solving problems

Next we will outline a specific step-by-step method of solving problems. This approach can be used by individuals, groups, couples, or families. If solving problems in a group or family, it is helpful to designate someone as the note-taker.

A. Problem-Solving Steps

1. Get the family together.
   It is essential to involve everyone in the problem-solving process. Meeting together ensures that everyone has a shared understanding of the problem and can contribute to the process. Families may choose to schedule a family meeting to discuss the problem.

2. Decide on a definition of the problem.
   Family members often have different perceptions of the problem, or may have different information related to the problem. This important step involves discussing the problem from everyone’s perspective and putting all the information together to define the problem clearly. It is important to be as specific as possible.

   This step also gives family members a sense of being valued and involved in discussions about the problem, which may lead to everyone’s being more actively involved in selecting and implementing a solution.

   These questions may help the family define the problem (McFarlane et al., 2002):
   - When did you first notice the problem?
   - When does it occur? (time of day, situation, common triggers, etc.)
   - Is the problem related to biochemical factors (e.g., changes in medication or substance abuse)?
   - How often does the problem occur?
   - Is the problem getting worse? At what rate?
   - Does the problem occur with certain people or under certain conditions?
   - Who is affected by the problem, and how?
   - What has been tried to alleviate the problem in the past? What was helpful?
   - With what activities does the problem interfere?

   Brainstorm as many possibilities as you can. It is important for everyone to voice at least one idea for the family to consider. All family members should refrain from criticism or evaluation of the suggestions during this step. Be creative and allow extreme solutions, as these may introduce an element of humor and help the brainstorming process.
4. **Do a cost-benefit analysis of each possible solution.**
   Discuss each possibility identified in the previous step. Identify and list the benefits of each solution and the possible costs (financial, emotional, time-wise, etc.). When providing negative feedback, be sure to criticize the idea—not the person who proposed the solution. Think about solutions tried in the past that did not work as sources of useful information. Consider that you may not have all the information necessary to select a good solution, or that the best solution might lie in a combination of solutions identified in Step 3.

5. **Decide on the best solution.**
   As a group, select one solution to implement, based on its practicality, its potential impact on the problem, the necessary resources, etc. The family’s agreement on the solution is essential to its effective implementation. If the family simply cannot agree, they may select one plan to try with the understanding that another option will be tried if this strategy doesn’t work.

6. **Develop a specific plan for how to implement the chosen solution.**
   Problem solving is not over just because you’ve selected a solution! Break the solution down into small, manageable, specific tasks. Select someone to carry out each task. You may also define feasible deadlines for each step.

7. **Evaluate whether the solution was attempted and whether or not it worked.**
   After step six, select a timeline for re-evaluation of the solution. At that time, reconvene to discuss the progress made to date, challenges encountered, and whether the problem has been solved. If a problem remains (or a new problem has emerged), discuss additional steps that need to be taken or whether a new solution is needed. You may need to repeat the problem-solving process if the new problem cannot be easily solved.

**B. Group Activity**

*Depending on the size of your group, break the class into small groups of four to five people. Guide each group to define a particular problem (possibly using an issue relevant to several members). Instruct each group to go through each of the problem-solving stages (using Handout L as a guide). Give the group 10-15 minutes to accomplish this task. Next, invite each group to share its process and decision with the class. Discuss their experience of the problem-solving activity.*

**Discussion Questions:**

- How would this strategy work at home with your loved one?
- What obstacles might you envision for using this approach?

*Engage the group in problem solving about how participants can adopt this process at home.*
Problem-Solving Skills for Families

Step 1: Define the problem.
Discuss the problem, being sure to include everyone’s opinion. Write down the exact definition of the problem.

Step 2: List possible solutions.
Record all ideas (without censoring!). Be sure that every family member proposes at least one idea for discussion.

Step 3: Discuss each possible solution.
Review each item in the list, and discuss the pros and cons of each option.

Step 4: Select the best solution.
Write down the chosen solution.

Step 5: Plan how your family will implement the chosen strategy.
Discuss what the family will need to accomplish the task, and who will do each step. It’s helpful to anticipate any potential challenges.

Step 6: Review the outcome.
Regardless of the outcome, praise each person’s efforts! If needed, you may revise your solution and/or return to your list of options to select another strategy.
Session Eight – Creating a Low-Stress Environment and Minimizing Crises

Materials Needed
Handout M: Tips on Creating a Low-Stress Environment and Minimizing Crises
Handout N: Tips on Getting the Most from your Psychiatric Medications
Handout O: Note cards for Role-Plays
Handout P: Resource List for Dealing with Emergencies

As discussed in previous sessions, mental illness is caused by a complex interaction between biochemical (e.g., heredity, genetics) and situational factors (e.g., life stress, coping resources, amount of social support). Both the emergence of the mental illness and the course of the disorder can be strongly affected by the consumer’s environment.

For all people, family life can provide great joy and a sense of connection/belonging. However, stressors in the family can be very difficult for everyone and may result in a worsening of symptoms for those with mental illness.

I. Importance of minimizing stress in the family

Previous sessions have addressed numerous potential stressors in family life, especially those involved in dealing with a loved one with mental illness. This session will explain why decreasing stress is important and provide specific tips as to how family members can do so. Even when the entire family strives to minimize stress, crises do arise. Therefore, we will create a crisis plan to help your family deal with these difficult times.

A. Research on the family environment (especially with schizophrenia and PTSD) has clearly demonstrated that the family atmosphere has a strong effect on the functioning of a person with mental illness. In fact, people living in families with high stress levels are more likely to relapse and/or be re-hospitalized (e.g., Tarrier, Sommerfield, & Pilgrim, 1999).
B. More specifically, research has focused on a term, *expressed emotion*, which refers to high levels of criticism, hostility, and emotional over-involvement in families. Research has demonstrated that consumers can stay out of the hospital longer and function better when families reduce the level of expressed emotion in the household. This session will provide some specific tips on how you can do so.

II. **Tips for creating a low-stress environment**

**Discussion Question:** What have you found to be helpful to keep the level of stress relatively low in your home?

*Distribute Handout M: Tips on Creating a Low-Stress Environment and Minimizing Crises*

1. **Have a predictable schedule.**
   a. Stress in a family is minimized when there is a predictable routine and schedule. For example, the family may eat dinner together every night at 6pm, go to church on Sunday mornings, go on walks on Saturday afternoons, etc. Individuals with a mental illness often struggle with changes (even small changes) in routine, so maintaining predictability is especially important.
   b. When a change in plans or departure from schedule can be anticipated, it’s helpful for families to discuss the shift in advance, so no one is surprised. Plans can be made for coping with possible stress that may arise.

2. **Maintain a calm atmosphere in the home.**
   a. Avoid excessive stimulation, such as unexpected visitors, loud music, violent television programming, etc.
   b. You and your loved one can discover and practice calming activities (e.g., playing quiet music, lighting candles).
   c. Ignore the “annoying but unimportant” things. The concept of “picking your battles” can be helpful, as some issues just aren’t worth arguing about!

3. **Define clear expectations for family members.**
   a. Families function smoothly when expectations for each person are clear and consistent. For example, assignment of household chores should be explicit and reviewed periodically.
   b. Make consequences for failure to meet expectations clear, consistent, and appropriate.
4. Share family rituals, including physical exercise.
   a. Families often bond with one another through shared rituals. Some families enjoy regular physical exercise, which can both strengthen relationships and release stress.
   b. Some families share religious/spiritual practices, such as church attendance, shared prayer, etc.
   c. Families may spend time together in nature.

5. Schedule and participate in regular family meetings.
   a. Families work well when they have a regularly scheduled time to discuss issues or problems. Selecting a time that can be adhered to weekly is important (e.g., after dinner on Sundays).
   b. Families may also use this time to plan family activities for the upcoming week.
   c. Effective use of problem-solving skills (see Session Seven) and communication skills (see Session Five) is important in family meetings.

6. Use your support networks and take breaks.
   a. At times family members feel reluctant to ask for help, but sometimes a few hours or days away can be refreshing. Develop a list of friends and/or family members who can pitch in when you need a break.
   b. Be sure to participate regularly in relaxing, fun activities for yourself. Your tolerance and ability to manage stress in the family will be much greater if you take good care of yourself.
   c. Explore community resources for possible respite care. Some facilities provide short-term care for individuals with serious mental illness, creating an opportunity for you to have time for yourself to recharge.

III. Encouraging medication compliance

Encouraging your loved one to take his/her medications can be extremely important. When consumers decide to discontinue their medications, they are at risk for relapse. The level of stress in the family can be kept low when consumers take their medications regularly and as prescribed.

Some family members help their loved ones by organizing the pillbox weekly, setting pills out at mealtime, and/or giving gentle reminders. Issues surrounding medication can involve power/control struggles in families, so use of effective communication and problem-solving skills is important.

* Distribute and discuss* Tips on Getting the Most from Your Psychiatric Medications (Handout N).
This handout was created for veterans, but includes reminders that are important for families to understand. You might choose to talk with your loved one about this handout. Even if he/she has heard these tips before, reviewing the themes can be helpful. Common sense is not always common practice.

Note the website listed on the handout: [www.safemedication.com](http://www.safemedication.com), which contains helpful, clear information about many medications (although it is not a substitute for talking to the doctor).

IV. Paying attention to “red flags”

Crises rarely emerge “out of the blue,” and families can be very helpful in preventing a relapse by learning about warning signs. Each person’s warning signs are different, so it is important to observe the specific cues for you and your loved ones.

A. A key task for family members is to pay attention to signs that their loved one may be decompensating. When families notice these early symptoms, a relapse or hospitalization may be avoided.

B. You may notice red flags in both the individual’s behavior and in how he/she interacts with others:

1. Individual red flags may include:
   a. Significant change in sleep patterns (sleeping much more or less than usual, worsened nightmares, etc.)
   b. Significant change in eating habits (eating much more or much less than usual)
   c. Refusing to take medications as prescribed (or at all) – may include “cheeking” pills
   d. Hearing voices or describing delusions (false beliefs)
   e. Increased agitation, such as being nervous, pacing, being irritable, having angry outbursts
   f. Increased depression and/or mood swings
   g. Social withdrawal (refusing to participate in family activities)
   h. Deterioration in personal grooming and dress
   i. Change in spending habits
   j. Paranoia or suspiciousness
   k. Using more illicit substances (alcohol/other drugs) or nicotine than usual
   l. Talking about suicide and/or homicide
   m. Others?

2. Red flags seen in your relationship with your loved one may include:
   a. Decreased communication
   b. Increased conflict or fighting
c. Change in sex life
d. Violence or threats of violence
e. Jealousy
f. Decrease in pleasant activities
g. Others?

C. When you notice these red flags, you can help your loved one by
   1. Encouraging him/her to contact the case manager/doctor. (If the consumer refuses, contact 911 or the provider yourself – especially in the face of a crisis such as when your loved one is making violent threats or behaving in a violent manner or appears to be experiencing psychotic symptoms.)
   2. Encouraging him/her to follow the treatment plan, including medications and therapies.
   3. Negotiating that each of you take a break and go to a quiet place to relax.
   4. Keeping alcohol and other drugs out of the house.
   5. Encouraging your loved one to stay in contact with his/her support system.

D. How you do these tasks is just as important as what you actually say. You can know the very best problem-solving (recall Session 7) or decision-making skills in the world, but you need to apply them in a supportive, encouraging manner.

E. More specifically, your loved one will be better able to hear you when you
   1. Express empathy, care and understanding for him/her.
   2. Approach him/her calmly. A soft and gentle tone of voice and talking slowly maximize the effectiveness of the communication.
   3. Listen quietly when your family member is sharing his/her concerns.
   4. Pay attention to nonverbal cues. For example, it’s important to give him/her space (rather than hovering over him/her), minimize distractions (e.g., TV, radio, etc.), and maintain appropriate eye contact.

V. Communication strategies for times of crisis

Because of the cyclical nature of mental illness, many consumers occasionally experience a crisis. During these times, consumers may experience very intense emotions, have difficulty thinking clearly, show poor judgment and insight into their situation, hear voices, feel very afraid and confused, act (or threaten to act) in aggressive ways, experience a flashback, threaten suicide, etc. Consumers usually have little awareness of the impact of their behavior on you. When alcohol or street drugs are involved, the situation may feel even more out of control.

These times can be very frightening for everyone involved, so getting professional help immediately is important. As we will discuss later in this session, knowing your local law enforcement/sheriff can be helpful if your loved one needs to go to the hospital.
Although you may feel overwhelmed and scared during these times, how YOU handle the stress can have a significant effect on the situation. Although easier said than done, the following suggestions can often be helpful in crisis situations:

1. Speak calmly, slowly, clearly and quietly to him/her. If it appears that your loved one isn’t listening to you, he/she may be distracted (e.g., by a flashback, hearing voices or experiencing other hallucinations, etc.).
2. Give him/her space. Avoid too much eye contact (which can increase his/her paranoia and fears) or physical contact. Don’t block the doorway (which can make him/her feel trapped).
3. Avoid threatening him/her. Doing so can further aggravate the consumer and may worsen the situation.
4. Call a trusted, calm friend or family member to help both of you. Keeping your discussions with your support people quiet and unemotional will foster a calmer atmosphere.
5. Avoid criticizing your family member. For example, you may be frustrated, thinking that his/her choice to discontinue taking the psychiatric medications caused this crisis. This is not the time to discuss medication compliance! Doing so will likely only further agitate your family member.
6. Avoid trying to reason with him/her. Remember that when people experience strong emotions, they aren’t able to think clearly—so arguing will only further provoke them. Also, trying to “talk someone out of” a delusion, hallucination, or flashback is usually counterproductive. Rather, listen calmly and in a nonjudgmental way.
7. As much as possible, comply with his/her requests (as long as they aren’t dangerous). It’s helpful to “pick your battles” and help the consumer feel “in control” as much as possible during this frightening time.

Modified from Tips for Handling a Crisis (http://www.schizophrenia.com/family/60tip.html)

**Group activity**

*Solicit two volunteers. Request that one volunteer play the role of the veteran (John, a 55-year-old man with PTSD) and the other volunteer be the wife (Mary, a 53-year-old woman). This couple has been married for 33 years. The volunteers will do two role-plays, the first demonstrating some unhelpful communication techniques and the second showing some helpful skills. Pay attention to what you observe.*

*Give each a note card with the following scenarios and ensure that they understand the situation (see Handout O for note cards):*

**Mary’s note card - SITUATION:** Although you love John very much and are aware of his genuine struggles with PTSD, he’s really been getting on your nerves lately. He hasn’t showered for over 4 days and has begun smoking cigarettes in the
house again, which really bugs you. To top it off, he’s now saying he doesn’t really feel like going to your granddaughter’s birthday party this weekend – an event you have been really looking forward to. You want to share your concerns with John.

**John’s note card - SITUATION:** This is a really difficult time of year for you, as you lost several buddies in a bad combat situation during this month many years ago. You’re feeling depressed, and have been irritated with Mary lately because she’s really nagging you. You’re anxious about the granddaughter’s birthday party this weekend because groups/crowds of people are difficult to be around. You wish Mary would just leave you alone.

**Mary will have different approaches in the two rounds of role-plays. For the first role-play, give her the following card:**

**Mary - Round One:** You really lay into him, venting all your frustrations from the past few months. Your tone of voice becomes loud and angry, and you tell him how sick and tired you are of his “pity party.” You just wish he’d “get over it” and get back to being the husband you married.

**For the second role-play, give her the following card:**

**Mary - Round Two** (new and improved Mary): Use the tools addressed in this session. Try the “softened start-up,” and acknowledge this as a difficult time of year for him (an anniversary of a traumatic event). Select one issue to address rather than dumping all the problems at once. You’re hopeful he will hear you.

**Discussion Questions:**

- How did it go?
- What are the benefits and costs of each approach?
- What skills did you notice Mary using in the 2nd role-play?
- What skills are toughest for you to use in real life?

VI. **Making a crisis plan**

Even with the best planning and prevention efforts, crises sometimes do occur. Given the cyclical nature of mental illness and the consequences of some consumers’ choices (e.g., not taking medications, using alcohol or other drugs), relapses and multiple hospitalizations are often part of the experience of mental illness.

A. You can prepare for potential crises in numerous ways.

_Distribute Handout P: Resource List for Dealing with Emergencies._

1. Create and post a list of emergency telephone numbers, including:
a. Local sheriff/police  
b. Case manager/doctor(s)  
c. Emergency room

2. Create a “hospital” pack, including:  
a. Insurance card/information  
b. List of current medications and dosages  
c. List of current medical problems  
d. List of mental health treatment history  
e. Clothes and personal belongings necessary for an admission

3. You might choose to talk to your employer about your loved one’s illness so your boss can be supportive if a family emergency develops.

4. You might also consider informing neighbors or friends of a potentially impending crisis. They may help with childcare, pets, or other household needs during a possible hospital admission.

B. If your loved one is admitted to the hospital, it’s helpful for you to:

1. Give him/her some space for about 24 hours to settle into the new environment.

2. Provide background information to the caseworker/social worker. You can be extremely helpful to the treatment team by giving this historical data.

3. Stay calm. When visiting your loved one, ignore the “small but annoying” behaviors. Be optimistic and focus on your hope for recovery. Encourage participation in the treatment plan.

4. Use this time to recharge. While he/she is in the hospital, you can catch up on some much needed sleep, relaxation, and time with friends.
Tips on Creating a Low-Stress Environment and Minimizing Crises

Create a low-stress environment.

1. Have a predictable schedule.
2. Maintain a calm atmosphere in the home.
3. Avoid excessive stimulation (e.g., frequent company, loud music).
4. Practice calming activities (e.g., playing quiet music, lighting candles).
5. Ignore the “annoying but unimportant” things.
6. Define clear expectations for every family member.
7. Share family rituals, including physical exercise, religious/spiritual activities, etc.
8. Schedule and participate in regular family meetings. Discuss any problems that arose during the week. Plan family activities for the upcoming week.
9. Use your support networks and take breaks.

Pay attention to “red flags.”

** If you see these warning signs, encourage your loved one to contact his/her provider. If he/she refuses and a crisis develops, call 911 or the doctor.

Individual red flags may include:
- Significant change in sleep patterns
- Significant change in eating habits
- Refusing to take medications as prescribed (or at all) – may include “cheeking” pills
- Hearing voices or describing delusions (false beliefs)
- Increased agitation, such as nervousness, pacing, irritability, angry outbursts
- Increased depression and/or mood swings
- Social withdrawal (refusing to participate in family activities)
- Deterioration in personal grooming and dress
- Change in spending habits
- Paranoia or suspiciousness
- Increased use of alcohol/other drugs or nicotine
- Comments about suicide and/or homicide

Red flags seen in your relationship may include:
- Decrease in communication
- Increased conflict or fighting
- Change in sex life
- Violence or threats of violence
- Jealousy
Tips for approaching your loved one

It’s helpful for family members to:

1. Express empathy, care and understanding for him/her.
2. Approach your family member calmly. Use a soft, gentle tone of voice. Talking slowly and clearly maximizes the effectiveness of the communication.
3. Listen quietly when your family member shares his/her concerns.
4. Pay attention to nonverbal cues. For example, it’s important to give him/her space (rather than hovering over him/her), minimize distractions (e.g., TV, radio, etc.), and maintain appropriate eye contact.

Managing Crises

You can prepare for potential crises in numerous ways.

1. You can post a list of emergency phone numbers, including:
   - Case manager / doctor(s)
   - Local sheriff / police
   - Emergency room
2. You can create a “hospital” pack, including:
   - Insurance card / information
   - List of current medications and dosages
   - List of current medical problems
   - List of mental health treatment history
   - Clothes and personal belongings necessary for an admission
3. You might choose to talk to your employer about your loved one’s illness.
4. You may consider informing neighbors or friends of a potentially impending crisis (so they can help with childcare, pets, etc.)

If your loved one is admitted to the hospital, it’s helpful to

1. Give him/her space.
2. Provide background information to the caseworker/social worker.
3. Stay calm. When visiting your loved one, ignore “small but annoying” behaviors, and focus on your hope for his/her recovery.
4. Use this time to relax and recharge.
Tips on Getting the Most from Your Psychiatric Medications

Key Points:

• *Take the medication every day.*

• *Be patient!* Many medications take 3-8 weeks to work, so it’s very important to continue taking the medication (even if you don’t feel better right away). Some disorders may take longer to respond, so ask your provider if you have concerns about your specific medication.

• *Do not stop taking the medications when you feel better.* Suddenly discontinuing some drugs can be dangerous and can cause your distressing symptoms to return. Rather, talk with your provider about your desire to safely decrease or change your medications.

• *Do not share medications.* Do not give other people your medications or use anyone else’s medications.

Memory Tips:

• Using a pillbox can be helpful.

• Take medication at the same time every day. It might help to take it when you do something else every day (such as every morning when you brush your teeth).

Side-Effects:

• If you ever feel you are experiencing a life-threatening reaction, call 911 or go to the emergency room immediately. If you believe you are a danger to yourself and/or others (thinking seriously about suicide or harming someone else), call 911 or go to the emergency room.

• Many side-effects improve the longer you take the medication.

• Write down side-effects caused by your medication, and talk to your provider about them. There may be a different drug with fewer and/or more tolerable side-effects that can work for you.

• If your provider/pharmacist has told you to take the medication with food, be sure to eat at least a few crackers to avoid an upset stomach.
Drug Interactions:

- Do not drink alcohol or use street drugs. Do not take over-the-counter medications without asking your provider or pharmacist first. Using these substances can be dangerous and prevents your medications from working.
- Whenever you receive a prescription for a new medication, inform your provider or pharmacist of your current medications and other things you take (such as vitamins, food supplements, natural products, etc.).

Final Hints:

- Ask your provider about the availability of therapies and/or classes that may be helpful. Research has shown that a combination of medication and therapies provides the quickest and most lasting treatment for many conditions. Participating in therapy can require extra time and effort on your part, but the benefits are often great.
- Finding a medication that’s right for you requires patience and teamwork between you and your provider. Sometimes the first medication you try may not be the best match for your symptoms. So, open and regular communication with your provider is very important!
- A website that provides helpful information about medications is: www.safemedication.com

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<thead>
<tr>
<th>Ambulatory Mental Health Clinic</th>
<th>(405) 270-5183</th>
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<td>(Monday – Friday, 8am-4:30pm)</td>
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<th>OKC VAMC Emergency Room</th>
<th>(405) 270-0501</th>
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<td>(24 hours/day)</td>
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Note Cards for Role-Plays

Mary’s note card - SITUATION:

Although you love John very much and are aware of his genuine struggles with PTSD, he’s really been getting on your nerves lately. He hasn’t showered for over 4 days and has begun smoking cigarettes in the house again, which really bugs you. To top it off, he’s now saying he doesn’t really feel like going to your granddaughter’s birthday party this weekend – an event you have been really looking forward to. You want to share your concerns with John.

John’s note card - SITUATION:

This is a really difficult time of year for you, as you lost several buddies in a bad combat situation during this month many years ago. You’re feeling depressed and have been irritated with Mary lately because she’s really nagging you. You’re anxious about your granddaughter’s birthday party this weekend because groups/crowds of people are difficult to be around. You wish Mary would just leave you alone.

For the first role-play, give Mary the following card:

Mary - Round One:

You really lay into him, venting all your frustrations from the past few months. Your tone of voice becomes loud and angry, and you tell him how sick and tired you are of his “pity party.” You just wish he’d “get over it” and get back to being the husband you married.

For the second role-play, give Mary the following card:

Mary - Round Two (new and improved Mary!)

Use the tools addressed in this session. Try the “softened start-up” and acknowledge this as a difficult time of year for him (an anniversary of a traumatic event). Select one issue to address rather than dumping all the problems at once. You are hopeful he will hear you.
Resource List for Dealing with Emergencies

It’s helpful to create this list BEFORE an emergency arises, such that you are prepared.

**Phone Contacts**
(in the event of an emergency):

- **Life threatening emergency:** 911
- **Local sheriff**
  - Name:
  - Phone number:
- **Local emergency room**
  - Name:
  - Phone number:
- **Case manager / doctor’s office**
  - Name:
  - Phone number:
- **Name of friend or relative you can call for support**
  - Name:
  - Phone number:
- **Local 24-hour/day hotline**
  - (Oklahoma City: 405-848-CARE )

**Current Psychiatric Medications:**

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<tr>
<th>Name</th>
<th>Dosage</th>
<th>Doctor who prescribed medication</th>
</tr>
</thead>
</table>

**Current Mental Health Diagnosis(es):**

**Current Physical Health Problems:**
Session Nine – What I Can Do
When My Family Member Is Angry or Violent

Materials Needed:
Handout Q: Anger Management – Time-Out Process
Handout R: Referrals for Domestic Violence

Brochures on local treatment options for anger-management difficulties

I. Anger – a normal human emotion

A. Just as with other feelings (e.g., sadness, joy), humans experience anger at different times and express the emotion in different ways.

B. Although many people think that being angry is wrong or bad, anger itself is not a problem. The behaviors that stem from this emotion can become problematic.

II. Important issues to consider about anger and violent behavior

A. Intense emotions may be a symptom of the mental illness. For example, one symptom of depression is increased irritability; and angry outbursts can be part of the experience of PTSD.

1. However, individuals can learn to control these strong emotions. Part of treatment often involves learning to be accountable for one’s behavior.
2. Your family member may try very hard to blame you for his/her behavior, sometimes using his/her mental illness/PTSD as an excuse. However, even if someone is struggling with serious emotional problems, it is never okay to harm another human being.

B. Research is finding that many veterans returning from Iraq and Afghanistan are having significant difficulties with anger. For example, one study of returning
service members found that 19% acknowledged problems with anger 4 months after homecoming (Bliese, et al., 2007). Another study of Iraqi/Afghanistan veterans seeking care in a VA medical center found that over half had conflicts with their partners involving “shouting, pushing, or shoving,” and over one quarter reported that this partner was “afraid of them” (Sayers et al., 2007).

C. Anger may be related to delusional thinking.

D. Anger and its expression may be strongly affected by substance use.

E. The presence of a head injury or traumatic brain injury (TBI) can also affect a person’s ability to manage anger effectively. In the Global War on Terrorism, more than one of five wounded have endured a TBI (often due to an improvised explosive device [IED], or roadside bomb) (Okie, 2005). People who have experienced this kind of injury are prone to increased irritability, aggression, and impulsive behavior – all of which can be challenging for relationships.

F. You may not have done anything to upset the person. Further, you are never responsible for your family member’s acting-out behavior (even if your behavior upsets him/her).

G. Anger may be the emotion that is expressed directly, but the individual may be experiencing a great deal of fear underneath the anger.

III. Common causes of anger in all human beings

(Note: These can be reality-based or not, such as with paranoia.)

A. Feelings of injustice (feeling somehow wronged or treated unfairly)

B. Feeling of personal or physical attack (feeling threatened by another person)

C. Feelings of inferiority or lack of control (put-downs, excessive criticism, being told what to do, feeling like you don’t have any choices)

D. Feelings of vulnerability (feeling exposed or afraid of being harmed, emotionally or physically)

Discussion Questions:

- What pushes your buttons (e.g., your family member’s not taking medications, refusing to go to the doctor, refusing to participate in family activities, not taking care of hygiene, drinking too much alcohol)?
• What pushes your family member’s buttons (e.g., being told what to do, being in overwhelming situations, feeling out of control)?

E. Although our science is not very good at predicting violent behavior, the best predictor of future violence is past violent behavior. Reflecting on the situations that surrounded previous acts of violence can provide clues as to potentially difficult situations in the future. This information may also guide efforts to prevent future violence.

IV. Effects of chronic anger

Discussion Question: How can chronic anger and/or inappropriate expressions of anger affect the family?

A. Strains interpersonal relationships
B. May lead to feelings of guilt, regret and shame
C. Can have adverse effects on communication (may not feel safe to express one’s feelings honestly for fear of consequences – so significant emotional distance may result)
D. May result in family members feeling like they are “walking on eggshells”
E. May be somatic/physical effects of chronic anger in family members (e.g., migraines, stomach problems, tension, jaw/temporo-mandibular joint pain)
F. May lead to physical violence, which is never acceptable, regardless of the cause

V. Cycle of violence: Episodes of violence have a predictable beginning, middle, and end.

Write stages on board. (Woolis, 1992)

<table>
<thead>
<tr>
<th>Phase One</th>
<th>Activation</th>
<th>Stress occurs.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phase Two</td>
<td>Escalation</td>
<td>Intervene now if possible.</td>
</tr>
<tr>
<td>Phase Three</td>
<td>Crisis</td>
<td>Violence may occur.</td>
</tr>
<tr>
<td>Phase Four</td>
<td>Recovery</td>
<td>Agitation lessens.</td>
</tr>
<tr>
<td>Phase Five</td>
<td>Stabilization</td>
<td>Guilt and remorse occur.</td>
</tr>
</tbody>
</table>
A. Family members often try to intervene in the most heated moments (in crisis or recovery phases). During these phases, people are not ready or able to take in information and discuss issues calmly.

B. However, intervening in the escalation stage has the highest likelihood of preventing an angry outburst.

C. Most effective communication can occur (and efforts made to prevent future violence) in phase five (stabilization).

D. If you ever feel in danger, immediately remove yourself from the situation and/or call 911. You should never stay in a frightening situation.

VI. Coping strategies for dealing with another individual’s anger

A. Be prepared.

1. Decide in advance what the limits are regarding your relative’s expression of anger. These limits need to be consistently enforced to be effective.

   **Example:** I will tolerate my family member raising his/her voice, but I will not put up with swearing or name-calling.

2. Decide in advance the consequences of such behavior.

   **Example:** I will walk away from the discussion if name-calling or swearing begins.

3. Discuss these limits with your loved one during a calm time. Clearly and concisely explain the limit without getting into a debate or justifying your rationale.

4. Follow through on the consequence every time. Otherwise, your family member will learn that he/she doesn’t have to abide by this limit and will push you the next time.

B. Stay calm and nonjudgmental.

C. Attempt to understand and acknowledge the person’s angry feelings. Often an individual escalates his/her expression of anger when feeling misunderstood. The intensity of the anger usually decreases when the person feels that the listener is genuinely trying to understand.

D. Choose your words wisely. Avoid generalizations (“you always…” or “you never…”), as these evoke retorts, counterattacks, and further polarization.
E. Avoid asking too many questions (can spark defensiveness and further anger).

F. Use *I* statements to report your own feelings.

   Example: When you yell at me, I feel hurt.

VII. **Time-out process**

A. Many parents use a time-out process in disciplining their children. Although the discipline strategy and this anger-management tool share the common goal of giving each party some time to cool down, the techniques are quite different.

B. This time-out process is a mutually agreed-upon strategy between equals (rather than involving a power differential such as in a parent-child relationship). Further, this technique helps people disengage from conflict early in the argument (to avoid further escalation), rather than functioning as a form of punishment.

C. This is an excellent process to negotiate with your family member in advance (during a calm time).

*Distribute Handout Q: Time-Out Process.*

1. **Review the process step by step.**
2. **Role play in session.**
3. **Brainstorm possible obstacles in applying it to participants’ relationship(s).**
4. **Problem-solve possible solutions.**

VIII. **Violence in relationships**

A. Threats of physical violence and/or actual violence are very important issues to address in families. Abuse should never be tolerated, as it is damaging to you, your family member, and your relationship.

B. Domestic violence is a significant issue in our families, as 25% of American women and 8% of men are raped and/or physically assaulted by a current/former spouse or partner at some time in their lives (Tjaden & Thoenees, 2000). The FBI estimates that a woman is beaten every 15 seconds in the United States.

C. Most people with mental illness are not violent; rather, many are socially withdrawn and quiet. Most research has not found a higher incidence of violence among people with mental illness than in the general population (Woolis, 1992). However, Vietnam veterans who have symptoms of PTSD are at increased risk for perpetrating acts of domestic violence (Beckham, Feldman,
Kirby, Hertzberg & Moore, 1997; Jordan et al., 1992; Riggs, 1997; Sherman et al., 2006).

D. Although large-scale research is not yet available regarding veterans from the Global War on Terrorism, clinical experience and preliminary data (Sayers et al., 2007) indicate that violence may be a significant problem (especially when substance abuse is also involved).

**Distribute list of local referrals for domestic violence (example shown in Handout R: Referrals for Domestic Violence).**

This list includes 24-hour crisis hotlines and emergency shelters. Shelters provide a safe place to stay, without the guilt of imposing on friends or extended family. Contact numbers for low-cost legal aid and victim protective orders (VPOs) are also listed.

IX. **Local treatment options for individuals dealing with anger-management issues**

**Example:** Oklahoma City VA Medical Center

A. Anger-Management Class – 8-week class that assists people with anger-management issues in identifying triggers for anger and learning effective ways of expressing it.

B. Couples or family therapy

C. Psychiatric medications
Anger Management
The Time-Out Process

Who? Time outs are helpful to use in relationships that you want to maintain. You would not use this procedure with strangers or with others with whom you have not already discussed the process.

When? Either partner can call a time out if a discussion/argument is starting to feel out of control. Most people cannot think clearly when angry, so postponing the discussion until both people are calmer is helpful.

**VERY IMPORTANT:** Discuss the use of this procedure at a calm time.

Key points to discuss:

1. Choose a mutually agreed-upon signal for the use of time out.
   
   Note: It is best to have both a verbal and nonverbal (hand signal) way of communicating the need to take a time out

2. Both agree that the partner will not follow the person who is taking the time out.

3. When someone calls a time out, end the discussion immediately. Trying to get in the last word is not helpful.

4. When you choose to take a time out, you need to tell the other person
   
   a. What you are going to do
   b. Where you are going (e.g., next room, for a drive, to a friend's house)
   c. When you will return (certain number of minutes/hours)

   **Example:** “I’m going to Wal-Mart to cool off, and I’ll be back in an hour.”

While taking the time out:

It is not helpful to obsess about how angry you feel at the other person during this time. Rather, it's a time to cool down so the discussion later can be more productive. Thinking about options for how to solve the problem can be helpful. You can consider what to do to improve the situation and make things work for both partners.
Upon returning to discuss:

1. The person who initiated the time out approaches his/her partner in a kind, gentle manner.

2. Each person presents his/her solution to the problem, and the other person listens without interrupting.

3. Both people focus on what aspects of the solution will work (rather than focusing on what won't work).

4. Together, choose parts of both solutions that will satisfy both parties.

Pointers for the discussion:

Do
- Be flexible.
- Listen carefully.
- Be open to compromise.
- Use I statements.

Don’t
- Focus on "all-or-none" solutions.
- Be rigid in only being open to your solution (e.g., “my way or the highway”).
- Criticize the other person for his/her ideas.

Local Treatment Options for Veterans Dealing with Anger-Management Issues

1. Anger-Management Class

2. Couples or Family Therapy

3. Psychiatric Medications

Adapted from presentation by Dan Jones, Ph.D., Clinical Psychologist
Referrals for Domestic Violence

Hotlines:

National Domestic Violence Hotline: 1-800-799-SAFE (7233)
- Crisis intervention
- Information about shelters
- Legal referrals
- Treatment options

Oklahoma City Sexual Assault Hotline: 405-943-RAPE

Domestic Violence Intervention Services (Tulsa): 918-585-3163

Shelters:

Oklahoma City Emergency Shelter: 405-949-1866 or 917-9922

Counseling:

Oklahoma City YWCA: 405-948-1770
Both individual (sliding-scale) and group (free) services are available.

Legal Aid:

Low-cost Legal Assistance:
- Oklahoma City: 405-521-1302
- Norman: 405-360-6631

Victims Protective Orders:

Victims Protective Order (VPO)
- Contact is Barbara Mason: 405-297-1139
- She is affiliated with both the police department and YWCA
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))
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.
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?

- 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.
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 anomic** (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:


*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. 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.

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

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 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…”).
Help Wanted

“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)]
Common Family Reactions to Mental Illness

Stages of Emotional Responses of Families to Mental Illness

“Emotional Stages of Response” [Dr. Joyce Burland (1990) The Journey of Hope (Family to Family Education Program)]

1. **Heads out of the sand** – Family realizes that the loved one has a mental illness.

2. **Learning to cope**

   - Families grow in acceptance of the illness.
   - A variety of emotions may intensify (e.g., anger, guilt, grief, etc.).

3. **Moving into advocacy**

   - Families may take on advocacy roles.
   - They may support other families that are struggling with similar issues.

Four Stages in the Caregiving Experience [Dr. David Karp, a sociologist at Boston College]

1. **Emotional disorganization/confusion** (before a firm diagnosis)

   - Fear and confusion about the loved one’s behavior
   - Uncertainty about how to feel
   - Questioning as to what I did wrong to cause the illness
   - Hope that the behavior will just go away

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
3. **Loss of dreams and resentment** (family realizes the illness may be a long-term condition)

During this stage, families may:
- Experience anger and resentment as they feel powerless to change the individual’s situation
- Revise their expectations of their loved one
- Experience role reversal
- Experience resentment when they have to give up their own goals and activities to help the loved one
- Become isolated from their social support
- Wonder about the loved one’s ability to control his/her behavior and struggle with how to interpret objectionable behaviors. Family members may ask “do we blame the person or the illness?” for this behavior. Families also wonder whether their loved one may be being manipulative at times (e.g., using the illness as an excuse).

4. **Recognition that families cannot control the consumer’s illness**

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, 2000, p. 20)
- Gain respect and admiration for the consumer’s struggle and strength

**Reminders about Family Reactions**

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 re-assess what is helpful at the time and what is not so helpful.

3. Seek support for yourself. Individuals with mental illnesses can be irritable and reject your help; they may be unappreciative of your support. 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.” Sponging is absorbing another person’s negative feelings and allowing them to control you; mirroring, on the other hand, involves simply reflecting back the other person’s negative feelings without “catching” the emotion.
Session Eleven - Taking Care of Yourself

Materials Needed:
Handout U: Taking Care of Yourself

I. Challenges of dealing with mental illness in the family

**Discussion Questions:**

- What is the hardest part of living with a family member who has a mental illness?
- What are the special challenges you face?

A. Long-term stress

1. As mental illness is usually not an acute situation, a family may experience many long-term demands and consequences.

2. John Talbott, former president of the American Psychiatric Association, described the increased toll on the family resulting from deinstitutionalization (trend of moving psychiatric consumers from hospitals to residing in the community, where they often live with family members) in the following manner:

   “…families have become the doctors, the nurses, and the social workers. But if the family has become the replacement for the ward staff, it is a staff without shifts, without backup, without ability to enforce daily routines or medication compliance, without techniques or rehabilitation or the ability to access records” (cited in Adamec, 1996, p. XV).
B. Grief

1. Family members may mourn the loss of a "normal" family life, as well as the loss of goals and dreams for the consumer and family unit.

   One father described this loss of dreams as, “You felt there was no limit to the possibility of his success. The possibility of him being President of the United States..." (Marsh, 1992, p. 94).

2. Accepting the reality of the loss is made more difficult by the cyclical nature of many mental illnesses. Family members may experience a roller coaster of emotions as the consumer’s level of functioning fluctuates. Families may feel very hopeful during times of stability, only to feel devastated when a relapse occurs.

3. Common stages of coping with any form of grief or loss (Kubler-Ross, 1969) include:
   - Denial (of the accuracy of the diagnosis and/or severity of the illness)
   - Bargaining
   - Anger
   - Depression
   - Acceptance (in this stage, family members may move into advocacy roles)

   One family member said, “You work through fear, anger, grief, and finally come to acceptance. Acceptance is like adopting someone new – the other person is no longer there and you have learned to look at your relative as he/she is now.” (www.psy.med.rug)

4. Family members often expend a great deal of energy coping with mental illness in the family.
   a. Financial
   b. Time and energy (monitoring family member’s well-being, going to doctor appointments, coping with hospitalizations, etc.)
   c. Coping with societal stigma surrounding mental illness, as well as others' expectations and attitudes about it
II. Emotional experience

Discussion Question: What are some emotions you experience in dealing with your loved one and his/her illness?

A. Caring about someone living with a mental illness can feel like a roller coaster, with a wide range of emotions. These common emotions often fluctuate in intensity and duration:

- worry
- anxiety
- protectiveness
- resentment
- shame
- anger
- guilt
- hopefulness
- depression
- frustration
- helpless
- powerlessness
- confusion
- fear
- embarrassment
- loneliness

B. Guilt is often an overwhelming feeling for families. For example, you may feel guilty for

1. Failing to recognize your loved one’s symptoms
2. Not seeking professional help earlier
3. Going out or doing something for yourself
4. Not "doing enough" – feeling like you're abandoning your family member
5. Not being “more patient”
6. A loss of or decrease in empathy for the person
7. Feeling angry or resentful (Thompson & Doll, 1982) or wishing you could escape the responsibility of caring for your loved one
8. Others?

C. Families may also feel unappreciated for the energy they spend caring for the consumer. Individuals with a mental illness often become self-absorbed, and they may experience family members’ assistance as intrusive. Consequently, consumers may be ungrateful and act in a critical manner toward others who are trying to help.

D. Some research has specifically examined the experience of being in a relationship with veterans with PTSD. These spouses/partners tend to have higher fears of intimacy (Riggs et al., 1998), lower relationship satisfaction (Jordan et al., 1992) and poorer psychological well-being (Calhoun, Beckham & Bosworth, 2002) in comparison with spouses of veterans without PTSD. In addition, partners of veterans with PTSD report quite high levels of depression and distress (Manguno-Mire et al., 2007).
III. Effects on family life

Discussion Questions:

- How has your loved one’s struggle with mental illness affected your personal life?
- Your family?

A. Long-term stress can result in exhaustion, physical illness, depression, increased use of alcohol or other drugs, insomnia, weight loss or gain, etc.

A large survey of family members revealed that distressed relatives used significantly more psychiatric medications and had more appointments with primary care physicians than relatives not feeling much distress (Schene et al., 1998).

B. Marriages and committed relationships in which one or both partners have a mental illness often involve numerous challenges. The couple’s social life is usually affected, as the consumer’s comfort level and interest in socializing may be decreased. The couple’s physical intimacy and sexual relationship may change, which can be caused by the mental illness and/or side-effects of medications. Financial hardship may arise, especially if the consumer was the primary breadwinner for the family.

C. In contrast, some family members report that their families have grown stronger through the experience of dealing with a mentally ill relative. Bonds among relatives can be strengthened. Family members can learn new coping strategies and become more compassionate people (Marsh & Johnson, 1997).

1. A mother of a mentally ill young woman learned that she “. . . can face adversity with courage. My husband and I are closer and more honest with each other as a result of our shared grief and stress” (Marsh et al., 1996, p. 10).

2. Another mother stated that, “It is gratifying to see our son’s courage as he deals with his mental illness” (Marsh et al., 1996, p. 9).

IV. The need for families to take care of themselves

A. To be effective, family members need to attend to their own well-being. Families who neglect their own needs can become “burned out” and have less energy to help their loved one. Research shows that family members do better when they
take care of themselves.

B. A good analogy for the importance of valuing your own needs can be seen in the direction that stewards or stewardesses give on every airline flight. They instruct parents to place oxygen masks on themselves before putting them on their children in an emergency. If parents fail to take care of their own needs first, they can be of little value to their children. Similarly, families can be much more effective in helping their loved one when they engage in regular self-care activities.

C. Some family members report feeling "selfish" when they take time to do things for themselves. However, they are often quite "selfless"; and neither extreme is healthy.

D. Healthy relationships involve give and take. Your situation often demands that much of your energy be given to your loved one. Therefore, finding ways to nurture yourself is especially important.

E. Draw Ven diagrams on board:

Healthy, Interdependent Relationship:  High Potential for Burnout and Loss of Self:

Family   Consumer   Family   Consumer

1. In the “healthy relationship” diagram, both individuals retain their own sense of “self” by having independent interests, friends (etc.). The “connection” is important to both parties, as they enjoy doing activities together and the closeness that evolves.

2. In the “high potential for burnout and loss of self” diagram, the family member loses a sense of self, as nearly all his/her time and energy is devoted to taking care of the person with mental illness. Consequently, the family member has little time and energy left over for self-care, and the cost can be high (physical well-being, mental health, spiritual health, etc.). Resentment can also occur in both the family and consumer in this situation. Both parties may also become quite isolated from their support networks. A move toward a
more mutual relationship is necessary to maintain a healthy balance.

V. Personal examples

**Discussion Question:**

- How can you tell when your stress level is high?

*Discuss common signs and symptoms of stress.*

- What are some effective ways to take care of yourself?

*Write ideas on the board.*

- Some suggestions to add if participants do not volunteer them:
  1. Monitor your physical health and blood pressure.
  2. Get 7-8 hours of sleep every night.
  3. Plan and do fun things for yourself: relax in a bubble bath, take a leisurely walk, get a massage, pray or engage in other spiritual activities, enjoy nature, work on a garden, call a friend, read a book or magazine, rent or go to a movie.
  4. Take a class at a local college or university.
  5. Try a new hobby.
  8. Seek out professional feedback and information (e.g., SAFE Program).
  9. Share responsibilities with other family members.
  10. Talk to someone who can understand your feelings and experiences.
  11. Give yourself time and permission to feel all your emotions. Consider expressing them via journaling, reading poetry, playing music, etc.
  12. Do something for someone else (e.g., grandchildren). Even when families feel very drained, they can re-energize by helping others.
  13. Consider seeking out a member of the clergy if spiritual input might provide comfort or reassurance.
  14. Look for the humor in the situation and find a way to laugh.

*Provide information about NAMI meetings (dates, times, location, contact person).*

*Distribute NAMI pamphlets.*

*Distribute Handout U: Taking Care of Yourself.* Go around the room and take turns reading each item. Discuss as a group. Have each participant put a star by two items and work on those two ideas in the next month.
Taking Care of Yourself

Dedicated to the family members and friends who support people living with mental illness…

1. Be gentle and patient with yourself. “You can hurry your life’s process along, but that would be like yelling at a flower to grow faster; it grows at its own pace…as will you” (anonymous).

2. Remind yourself that you are a loving helper, not a magician. None of us can change anyone else – we can only change the way that we relate to others.

3. Find a place where you can be a hermit; use it every day, or when you need to.

4. Learn to give support, praise, and encouragement to those around you – and learn to accept it in return.

5. Remember that, in light of all the pain we see around us, we are bound to feel helpless at times. We need to be able to admit this without shame. Just by caring and being there, we are doing something important.

6. Learn to vary your routine often and to change your tasks whenever possible.

7. Learn to know the difference between complaining that relieves tension and complaining that reinforces it.

8. At the end of every day, focus on one good thing that happened during the day.

9. Become a resource to yourself! Be creative and open to new approaches to old things.

10. Use the support you give to others or a “buddy” system regularly. Use these as a support, for reassurance and for re-focusing yourself.

11. Learn to use the expression “I choose to…” rather than expressions like “I have to,” “I ought to,” or “I should.”

12. Learn to say, “I won’t” rather than “I can’t.”

13. Learn to say “no” and mean it. If you can’t say “no,” what is your “yes” worth?

14. Being aloof and indifferent is far more harmful than admitting to an inability to do more.

15. Above all else – learn to laugh and to play! - Author Unknown
Session Twelve – Skills for Managing Stress Effectively as a Family Member

Materials Needed:
Handout V: My Coping Skills Toolbox
Handout W: Everyday Survival and Stress-Busting Kit

“Survival kits”
Brochures on local treatment options for veterans with stress-management difficulties

I. Definition of stress

Discussion Question: The term _stress_ is used loosely in our culture. What does it really mean?

A. One definition = “physical, mental and emotional reactions that occur as the result of changes in one’s life and demands in life.”

B. Stressors can be classified in three different categories:

1. Major life events

   a. Examples may include divorce, death of a loved one, loss of job, marriage, etc.

   b. Other events are specific to living with mental illness, such as a hospital admission, suicide attempt, psychotic episode, etc.

   c. Both seemingly positive and negative events can produce stress. Eustress = “positive stress” and distress = “negative stress.”
2. Daily hassles
   a. Daily hassles can include such events as traffic congestion, parking difficulties, petty arguments, etc.
   b. They can also be specific to living with mental illness, such as struggling with your loved one to maintain appropriate hygiene and grooming, monitoring medication issues, feeling burdened by household responsibilities, etc.
   c. Small hassles can accumulate and result in significant stress.
   d. Sometimes coping with these daily issues can consume more energy than dealing with the major, intermittent problems.

3. Chronic life situations
   a. These include situations such as single parenting, racism, discrimination, major physical health problems, etc.
   b. Because of the long-term nature of mental illness, caring about or living with someone with a mental illness can also be a chronic stressor. Research has found that caring for an ill or disabled spouse has been associated with increased risk of coronary heart disease (Lee, Colditz, Berkamn & Kawachi, 2003), depression, and other physical health problems. Therefore, finding ways of taking care of yourself physically and emotionally is very important!

Discussion Question: What are greatest sources of stress for you?

II. How you experience stress

Activity: List on the board the following four major categories, and ask participants to discuss these common manifestations of stress:

A. Physical: Chemicals are released by glands in the brain when stress occurs, often resulting in the following symptoms:

   Headaches, changes in sleep, indigestion, neck/shoulder tension, sweaty palms, increased risk for becoming physically ill, increased blood pressure, rapid heart rate, rapid respiration, heavy perspiration, dilation of pupils, slowing of digestion, feeling a rush of strength, etc.
B. **Emotional:** Stress takes an additional toll on human beings, which can be evident in changes in emotional states:

Irritability, impatience, yelling, being jumpy, inability to concentrate, feeling on edge, loneliness, feeling isolated

C. **Behavioral:** Behaviors may also change when a person is under stress. People tend to be more:

Demanding, controlling, impatient, overly critical, prone to procrastination, withdrawn, likely to engage in overeating or abuse of alcohol (or other addictive behaviors), etc. than they would normally be.

D. **Cognitive:** Although the connection may not be readily apparent, a person’s thinking may also change when experiencing a great deal of stress. Individuals tend to be more:

Forgetful, distractible, mistake-prone, unable to remember things, serious (loss of humor or creativity), etc.

III. **Vulnerability to stress**

**Discussion Questions:**

- How vulnerable are you to stress?

- When do you feel more vulnerable to being overwhelmed by stress?

A. All people have times when they are more vulnerable to stress, such as when they are physically ill or tired, have had a long day, experience extended periods of bad weather, etc.

B. Chronic conditions (e.g., chronic pain, inadequate social support, family problems, etc.) can make people more “on edge” than usual and more likely to feel stress.

C. Poor health habits and choices (e.g., getting insufficient sleep, drinking too much caffeine, abusing alcohol or illicit drugs, having poor nutrition, not getting regular exercise) can also make people more vulnerable to stress.

D. People can do preventive maintenance (just as with a car) to be more resilient to the stress that is an inevitable part of life.
IV. Skills for managing stress effectively

*Activity:* Brainstorm and write on the board various coping skills.

*Examples:* Writing or journaling, engaging in crafts or hobbies, exercising, crying, talking to trusted friend or family member, doing spiritual practices (prayer, meditation), etc.

*Distribute Handout V: My Coping Skills Toolbox.* Have each participant list five existing tools and five new tools he/she plans to try.

*Activity:* Teach progressive muscle relaxation exercise, and practice in session. Discuss the importance of regular practice of skill for it to be effective.

*Activity:* Teach breathing exercise.

1. *Breathe in to count of eight – slowly breathe out to count of eight. Repeat several times.*

2. *Discuss the importance of regular practice of skill for it to be effective.*

*Distribute Handout W: Everyday Survival and Stress-busting Kit and have participants read aloud what each item represents.*

V. Local treatment options for stress management

*Example:* Oklahoma City VA Medical Center

A. Anxiety/stress-management skills class – this eight-session class addresses both the cognitive (e.g., self-talk, mistaken beliefs) and behavioral (e.g., relaxation, imagery) components of anxiety.

B. Biofeedback program – this treatment option involves providing immediate feedback on several bodily functions, with the goal of enhancing one’s ability to exert control over these processes and to relax.

C. Coping skills/crisis intervention groups – the Crisis Intervention Program provides daily group therapy sessions for veterans who are psychiatrically stable but are experiencing a distressing major life event (e.g., divorce, loss of job).
My Coping Skills Toolbox

**Existing Tools:**

1. 
2. 
3. 
4. 
5. 

**New Tools I Will Try:**

1. 
2. 
3. 
4. 
5.
Everyday Survival and Stress-Busting Kit

**Toothpick**  
To remind you to pick out the good qualities in others.

**Rubber Band**  
To remind you to be flexible; things might not always go the way you want, but it will work out.

**Band Aid**  
To remind you to heal hurt feelings, yours or someone else’s.

**Pencil**  
To remind you to list your blessings every day.

**Eraser**  
To remind you that everyone makes mistakes, and it’s okay!

**Chewing Gum**  
To remind you to stick with it and you can accomplish anything.

**Candy Kiss**  
To remind you that everyone needs a kiss or a hug every day.

**Tea Bag**  
To remind you to relax daily and go over that list of your blessings.

To the world, you may just be somebody…
but to somebody, you may be the world.

Support And Family Education:
Mental Health Facts for Families
Michelle D. Sherman, Ph.D.
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.

Discussion Question: 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. **Discomfort with feeling dependent**

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. **Delusional thinking**

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.
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. **Uncertainty about how to obtain services**

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.

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.
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).
What To Do When Help Is Turned Away

Why do people living with mental illness sometimes reject help?
1. Denial that they have a problem and/or need help
2. Pessimism about effectiveness of treatment
3. Impaired insight
4. Discomfort with feeling dependent on anyone
5. Delusional thinking
6. Poor relationships with doctors
7. Unpleasant side-effects of medications
8. Enjoyment of some symptoms of the illness (e.g., high energy levels associated with mania)
9. Fear of being out of control
10. Uncertainty about how to obtain services
11. Stigma surrounding seeking mental health care
12. Finances

Common feelings in family members when help is turned away
- frustration
- disappointment
- depression
- resentment
- hopelessness
- helplessness
- confusion
- powerlessness

Tips for coping when help is rejected
1. Remember that you are not responsible for his/her behavior.
2. Remind yourself that your loved one is not rejecting you – rather, he/she is having difficulty allowing others to help.
3. Seek support for yourself.
4. Calmly express your worry and disappointment to your loved one about his/her choices.
5. Remind your loved one of the availability of others who care and who could be of help (e.g., hotlines, professionals, other family members, friends).
6. Remind your loved one of how well he/she was doing when taking medications regularly and participating in treatment in the past.
7. Don’t give up. Try to be patient.
8. Ask if there are any other specific ways that you can help.
9. Remember that mental illness often has ups and downs.
10. Remember the 3 Cs from Alanon: Cause, Cure and Control: You did not cause the mental illness; you cannot cure it; and you cannot control his/her behavior.


Support and Family Education:
Mental Health Facts for Families
Michelle D. Sherman, Ph.D.
**Session Fourteen: Do’s and Don’ts in Helping your Family Member**

**Materials Needed:**
- Handout Y: Tips by a Panel of Experts on Caring About Someone with a Mental Illness
- Handout Z: Do’s and Don’ts in Helping Your Family Member or Loved One
- Handout AA: What We Want Our Family Members and Friends to Know

**I. Activity**

*Depending on the number of participants, break into groups of three or four.*

1. **Distribute** Handout Y: Tips by a Panel of Experts on Caring about Someone with a Mental Illness.

2. **Review the instructions:**

   “We, as family members and friends, know that caring about someone with a mental illness can be challenging, physically, emotionally, and spiritually. We have developed a great deal of expertise in knowing how to help our loved ones. If we were to meet someone who recently had a family member diagnosed with a mental illness, we could be very helpful to him/her.

   “The following are our group’s best tips on helping your loved one.”

   *Allow approximately 10-15 minutes for the groups to create the lists of “Top Five Do’s” and “Top Five Don’ts.”*

   *Come back to the large group, and have each group present its lists.*

   *Write tips on the board, and discuss the themes in the lists.*
II. **Review other helpful DO’s**: (parts adapted from Woolis, 1992)

*Distribute Handout Z: Do’s and Don’ts in Helping Your Family Member or Loved One.*

A. Communication:

1. Be respectful and calm.
2. Stick to one topic at a time.
3. Keep a positive attitude.
4. Be honest with yourself and with your family member.
5. Use humor (when appropriate).
6. Communicate openly and often with the doctors.

B. Building family member’s self-esteem:

1. Work together to create short-term goals.
2. Stay active – plan and engage in activities together.
3. Genuinely praise and compliment your loved one frequently, even for day-to-day behaviors.

C. Dealing with difficult behavior:

1. Accept the fact that the consumer has a legitimate illness.
2. Set and discuss clear limits, rules and expectations for the family member’s behavior.
3. Be consistent and predictable.
4. Keep a log of your loved one’s symptoms, response to various medications, hospitalizations, etc. This information can be very valuable to his/her doctors.

   **Remind participants of the Log of Mental Health Treatment in the “Empowering Your Loved One in the Journey of Recovery” session (Session 16).**

5. Pay attention to warning signs of possible relapse, worsening of symptoms, etc.

6. Give your family member space when he/she asks for it (as long as he/she is not dangerous to him/herself or others).

D. Taking care of yourself:

1. Stay in contact with your support system.
2. Educate yourself about mental illness.
3. Talk to other people struggling with similar situations (such as at the SAFE Program, meetings of NAMI, etc.).
4. Remember that you are not alone.
5. Take 1 minute at a time.

III. Review other helpful DON’Ts: (parts adapted from Matsakis, 1988 and Woolis, 1992)

A. Communication:
   1. Don’t tease your family member about his/her symptoms.
   2. Don’t yell or shout at your family member.
   3. Don’t argue with your family member about his/her symptoms (e.g., don’t try to talk him/her out of delusions or hallucinations).
   4. Don’t get stuck in talking about the past – stay in the present.

B. Dealing with difficult behavior:
   1. Don’t take the symptoms or illness personally.
   2. Don’t tolerate abuse of any kind from your family member.
   3. Don’t blame all your family member’s undesirable behaviors on the mental illness.
   4. Don’t always interpret his/her emotional distance as reflecting something about your relationship.

C. Dealing with the fact that your family member has a mental illness:
   1. Don’t let the illness run your life.
   2. Don’t try to be your family member’s therapist.

D. Enhancing your family member’s self-esteem:
   1. Don’t make all the decisions for your loved one – allow him/her to make as many decisions as possible.
   2. Don’t tell your family member to just “get over it” or to “get a life.”
   3. Don’t call your family member names (e.g., psycho, crybaby, etc.).

IV. Informal survey

A group of consumers with chronic mental illness was asked to create a list of do’s and don’ts for family members. This list is quite similar to the suggestions detailed above.

Distribute Handout AA: What We Want Our Family Members and Friends To Know
(Created by a group of consumers at the Oklahoma City VA Medical Center, September 21, 1999, reproduced with permission of the consumers)

Discuss participants’ reactions to the list.
Tips by a Panel of Experts on Caring About Someone with a Mental Illness

We, the undersigned, know that caring about someone with a mental illness can be challenging: physically, emotionally, and spiritually. We have developed a great deal of expertise in knowing how to help our loved ones. If we were to meet someone who recently had a family member diagnosed with a mental illness, we could be very helpful to him/her.

The following are our group’s best tips on helping your loved one:

**Top Five Do’s in Helping Your Loved One:**

1. 
2. 
3. 
4. 
5. 

**Top Five Don’ts in Helping Your Loved One:**

1. 
2. 
3. 
4. 
5. 

Signatures of the Experts:

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

Support And Family Education:
Mental Health Facts for Families
Michelle D. Sherman, Ph.D.
Do’s and Don’ts in Helping Your Family Member or Loved One

Helpful DO’s:

A. Communication:

1. Be respectful and calm.
2. Stick to one topic at a time.
3. Keep a positive attitude.
4. Be honest with yourself and with your family member.
5. Use humor (when appropriate).
6. Communicate openly and often with the doctors.

B. Building family member’s self-esteem:

1. Genuinely praise and compliment your loved one frequently, even for day-to-day behaviors.
2. Work together to create short-term goals.

C. Dealing with difficult behavior:

1. Accept the fact that the person has a legitimate illness.
2. Set and discuss clear limits, rules, and expectations for the family member’s behavior.
3. Be consistent and predictable.
4. Keep a log of your loved one’s symptoms, responses to various medications, hospitalizations, etc.
5. Pay attention to warning signs of possible relapse, worsening of symptoms, etc.
6. Give your family member space when he/she asks for it (as long as he/she is not dangerous to him-/herself or others).

D. Taking care of yourself:

1. Stay in contact with your support system.
2. Educate yourself about mental illness.
3. Talk to other people who are struggling with similar situations (such as at the SAFE Program, meetings of NAMI, etc.).
4. Remember that you are not alone.
5. Take 1 minute at a time.

Support And Family Education:
Mental Health Facts for Families
Michelle D. Sherman, Ph.D.
Helpful DON’Ts:

A. Communication:

1. Don’t tease your family member about his/her symptoms.
2. Don’t yell or shout at your family member.
3. Don’t argue with your family member about his/her symptoms (e.g., don’t try to talk him/her out of delusions or hallucinations).
4. Don’t get stuck in talking about the past – stay in the present.

B. Dealing with difficult behavior:

1. Don’t take the symptoms or illness personally.
2. Don’t tolerate abuse of any kind from your family member.
3. Don’t blame all your family member’s undesirable behaviors on the mental illness.
4. Don’t always interpret his/her emotional distance as reflective of something about your relationship.

C. Dealing with the fact that your family member has a mental illness:

1. Don’t let the illness run your life.
2. Don’t try to be your family member’s therapist.

D. Enhancing your family member’s self-esteem:

1. Don’t make all the decisions for your loved one – allow him/her to make as many decisions as possible.
2. Don’t tell your family member to just “get over it” or to “get a life.”
3. Don’t call your family member names (e.g., psycho, crybaby, etc.).

What We Want our Family Members and Friends to Know

Created by a Group of Individuals Living with Serious Mental Illness
Oklahoma City VA Medical Center

Reproduced with permission of the group, September 1999

1. Please learn about my mental illness – the more you understand, the better we can get along.

2. I want more input on how my money is handled.

3. Please be more patient with me.

4. Please get involved in my treatment, such as through the SAFE Program.

5. Please don’t criticize me. Try to be more tolerant of me – and of my sometimes confusing behaviors.

6. Please try to learn more about my medications and their side-effects; you can talk to the doctor, and get a printout of information about each medication.

7. Please pay attention to my needs as an individual – not just a “mental patient.”

8. Remember that I may be uncomfortable in large groups.

9. Remember that I am still “human” and that I want to give my input in different situations.

10. Please give me as much independence as you can.

11. Remember that I need friends and intimacy.

12. Help me to keep learning – help me find opportunities to learn through classes, hobbies, crafts, etc.

13. Be aware that mental illness is different for each person.

14. Remember that I may feel guilty, embarrassed and bad about myself because of the way others treat me.
Session Fifteen - Rights and Responsibilities of Consumers, Family Members, and Professionals

Materials Needed:
Handout BB: Rights and Responsibilities of Consumers, Family Members, and Professionals

Consumers, family members, and professionals all have certain rights and responsibilities. The roles and extent of involvement of these three groups vary, depending upon the level of functioning of the consumer at the time. Consumers and family members often feel overwhelmed by “the system” and unsure how to navigate the sometimes confusing channels. Consequently, knowledge of these rights can be very helpful.

Consumers and family members also have numerous important responsibilities. Although these tasks may not seem like “responsibilities,” they are choices individuals can make that maximize the wellness of the consumer and family unit.

Distribute Handout BB: Rights and Responsibilities of Consumers, Family Members, and Professionals.

I. Rights and responsibilities of consumers (parts adapted from Bisbee, 1991)

A. Rights of consumers

1. To be protected from abuse (from family members and professionals). As consumers are often in somewhat vulnerable positions, safeguards are important to ensure their protection and humane treatment.

2. Not to be blamed for the mental illness.
3. To be educated about the illness and treatment options. Seeking out information about symptoms and treatment options can be therapeutic. Consumers may wish to solicit information in a variety of formats (e.g., discussions with providers, videos, pamphlets) and on repeated occasions.

4. To be given timely and appropriate treatment in a safe, therapeutic environment.

5. To participate (to the fullest extent possible) in treatment planning and decision-making. To be able to consent to or refuse treatment. As consumers often feel somewhat out of control of their lives, professionals should actively empower them to be involved in healthcare decisions.

6. To communicate with family members, friends, clergy and attorneys.

7. To have their treatment information and medical records kept confidential (except in specific situations when the information needs to be released).

8. To have copies of treatment and medical records if requested (unless deemed inappropriate at the time by the professional).

Discussion Questions:

- Would anyone wish to share an experience in which your loved one stood up for his/her rights?
- Or you stood up for his/her rights?

B. Responsibilities of consumers

1. To learn about and accept the illness.

2. To obtain appropriate treatment.

3. To cooperate with professionals’ directions (e.g., medication compliance, attending and participating in other treatment options).

   a. Due to a variety of reasons (see Session 13, “What to Do When Help is Turned Away”), consumers may fail to uphold these responsibilities, resulting in frustration for families and professionals. Discussing the reasons for these choices may increase the family’s understanding and the consumer’s acceptance of the responsibilities.

   b. For example, a consumer may dislike the decreased libido side-effect of an anti-depressant so may just discontinue the medication. If this reason
could be addressed openly, perhaps another medication could be used that would not have this adverse side-effect.

II. Rights and responsibilities of family members (parts adapted from Bisbee, 1991)

A. Rights of family members

1. To be protected from abuse (from consumers and professionals).

2. To be free from blame for the mental illness. Family members often assume too much responsibility for having “caused” the consumer’s mental illness. Professionals need to combat this misperception by explaining the multiple causes of the illness.

3. To be educated about the illness and treatment options.

4. To access information on advocacy and support (such as through the SAFE Program, the local NAMI affiliate, etc.).

5. To visit the consumer if he/she is in the hospital (during defined visiting hours).

6. To call the police or sheriff at any time if your loved one is an imminent danger to him-/herself or others. The professionals will make the decision whether or not the consumer can be detained against his/her will, but family members can always make the report when concerned about their loved one’s safety.

Discussion Question: Can you think of other rights you as family members have?

B. Responsibilities of family members

1. To learn about and accept the illness.

2. To share your experiences and observations of your loved one with the professionals. See more details for interacting effectively with providers in Session 16: “Empowering Your Loved One on the Journey of Recovery.”

3. To have your loved one sign a release-of-information form (if he/she agrees), allowing the provider to speak freely with you as family. If your
loved one refuses, you can still convey your concerns to the doctors (e.g., call them on the telephone, leave a message, write a letter). However, the doctor cannot tell you any specific information about your loved one without a signed release.

4. To encourage your family member to comply with the professionals’ treatment plans. Your loved one likely values your opinion (even if he or she doesn’t show it), so your encouragement to follow doctors’ directions can be very influential. Your loved one can sense if you don’t believe in the treatment plan, so educate yourself so you can support the doctors’ recommendations.

5. To take good care of your own physical and emotional health.

6. To monitor your loved one for signs of dangerousness (to him/herself or others).

III. Rights and responsibilities of professionals (parts adapted from Bisbee, 1991)

Mental health professionals also have important rights and responsibilities.

A. Rights of professionals

1. To be protected from abuse (from consumers and family members).

2. To not have a cure or a “quick fix.” As much as consumers, families and professionals would like an easy cure for mental illness, all parties must struggle with the existence of these disorders. Our science has made significant advances in understanding the causes of mental illnesses and discovering new treatments. Research and learning will continue to improve the quality of life for individuals with a mental illness.

3. To be given timely and honest information about the consumer’s functioning.

   a. Intentionally withholding important information from professionals severely impairs their ability to effectively help. Only when doctors are given honest information about consumers are they able to use their skills effectively.
b. Example: Your 28-year-old son has been struggling with depression for 4 years. The psychiatrist has been trying him on several different antidepressants and group therapies, but none seems to be helping. You know that your son is drinking six to eight beers per night (and more on weekends), but he tells the psychiatrist that he just drinks “socially.” What could you do? (Talk to your son about your concerns; tell the psychiatrist, etc.)

4. To make honest mistakes. Although doctors are often seen as “super-human,” they, too, make honest mistakes and poor decisions and have their own “bad days.” None of these factors, however, should excuse poor care.

5. To have a personal life that consumers and family members respect, while always providing back-up coverage (colleague, emergency room, etc.). Although consumers may want their provider to be available to them 24 hours a day, professionals have the right to boundaries on their personal lives. Some movies (e.g., What About Bob? with Bill Murray and Richard Dreyfuss) portray consumers’ failures to respect these boundaries (e.g., going to the doctor’s home, following the doctor on vacation, befriending family members).

B. Responsibilities of professionals

1. To do no harm. Sadly, the media often portray mental health professionals doing significant emotional damage to their consumers (e.g., being friends with them, sexualizing the therapeutic relationship, taking advantage of vulnerable individuals, etc.). However, all mental health professions have strict codes of ethics (e.g., American Psychological Association’s Ethical Principles of Psychologists and Code of Conduct) that mandate appropriate behavior. Stringent consequences are enforced for violations of the standards (e.g., lose license to practice, be placed on probationary status).

2. To provide consumers with an accurate diagnosis of their condition (as well as information about prognosis).

3. To prescribe appropriate medications (if indicated) and educate consumers about possible side-effects (this is most commonly done by psychiatrists).

4. To protect the confidentiality of the consumer and family members, as mandated by state law.

5. To stay informed of current research on treatment options (new medications or therapies) and use this information to guide their clinical practice. Given the rapid pace at which progress is being made in the understanding and treatment of mental illness, providers need to keep current (via research, workshops, reading journals, etc.)
6. To treat all consumers and family members with respect.

7. To acknowledge and foster strengths in the consumer and family

8. To direct consumers and family members to opportunities for education, support, and advocacy.

Treatment is most effective when consumers, family members, and professionals work together to understand, monitor, and treat the consumers.

IV. What to do if you believe your family member’s rights are being violated

A. Talk to the provider. Perhaps a misunderstanding has occurred, and a frank discussion with the professional would allow clarification of the situation.

B. Consider requesting a change of provider.

C. Request an appointment with the management of the agency or medical center.

D. Ask for a listing of patient rights at the facility.

E. Contact your local NAMI affiliate for support and guidance. A major priority of NAMI is to advocate for improved services for consumers with mental illness.

F. Learn the laws in your state.
Rights and Responsibilities
of Consumers, Family Members and Professionals

I. Consumers

A. Rights
   1. To be protected from abuse.
   2. To be free from blame for the mental illness.
   3. To be educated about the illness and treatment options.
   4. To be given timely and appropriate treatment in a safe, therapeutic environment.
   5. To participate in treatment planning and decision-making. To be able to consent to or refuse treatment.
   6. To communicate with family members, friends, clergy and attorneys.
   7. To have their treatment information and medical records kept confidential (except in specific situations when the information needs to be released).
   8. To have copies of treatment records if requested.

B. Responsibilities
   1. To learn about and accept the illness.
   2. To obtain appropriate treatment.
   3. To cooperate with the professionals’ directions.

II. Family Members

A. Rights
   1. To be protected from abuse.
   2. To be free from blame for the mental illness.
   3. To be educated about the illness and treatment options.
   4. To have access to information on advocacy and support.
   5. To visit the consumer if he/she is in the hospital.
   6. To call the police or sheriff at any time if you feel that your loved one is an imminent danger to him/herself or others. The professionals will make the decision whether or not your loved one can be detained against his/her will, but you can always make the report when concerned about issues of safety.

B. Responsibilities
   1. To learn about and accept the illness.
   2. To share your observations of your loved one with the professionals.
   3. To encourage your family member to comply with his/her treatment plan.
   4. To take good care of your own physical and emotional health.
   5. To seek out advocacy and support groups for yourself.
   6. To monitor your loved one for signs of dangerousness (to him/herself or others).

Support And Family Education:
Mental Health Facts for Families
Michelle D. Sherman, Ph.D
III. Professionals

A. Rights
   1. To be protected from abuse.
   2. To be given timely and honest information about your loved one’s functioning.
   3. To make honest mistakes.
   4. To have a personal life that your family members respect, while providing back-up coverage if needed.

B. Responsibilities
   1. To do no harm.
   2. To provide individuals with mental illness an accurate diagnosis of their condition.
   3. To prescribe appropriate medications (if indicated) and educate individuals and family members about possible side-effects.
   4. To protect the confidentiality of the individual undergoing treatment and family members, as mandated by state law.
   5. To stay informed of current research on treatment options and to use this information to guide clinical practice.
   6. To treat all individuals living with mental illness and family members with respect.
   7. To acknowledge and foster strengths in the family.
   8. To direct individuals with mental illness and family members to opportunities for education, support, and advocacy.

IV. What you can do if you believe that your family member’s rights are being violated

   1. Talk to the provider.
   2. Consider a change of provider.
   3. Set an appointment with the management of the agency/medical center.
   4. Ask for a listing of patient rights at the facility.
   5. Contact your local National Alliance on Mental Illness (NAMI) affiliate for support and guidance.
   6. Learn the laws in your state.

Parts were adapted from Educating Patients and Families About Mental Illness, Copyright 1991, 1995, Cynthia Carson Bisbee, Ph.D. Used by permission. To order manual, call Therapeutic Resources: 1-888-331-7114 (www.therapeuticresources.com)
Session Sixteen – Empowering Your Loved One on the Journey of Recovery

Materials Needed:
Handout CC: Character Strengths
Handout DD: My Perception of My Family Member’s Current Functioning
Handout EE: Log of Mental Health Treatment

You may have heard the term *recovery* mentioned in the mental health arena in the past few years. What does it mean?

According to the National Consensus Statement on Mental Health Recovery (created by the Substance Abuse and Mental Health Services Administration’s Center for Mental Health Services), recovery is:

“A journey of healing and transformation enabling a person with a mental health problem to live a meaningful life in a community of his or her choice while striving to achieve his or her full potential.”

Discussion Questions:
• What does that mean to you?
• How do you feel your loved one is progressing on his/her journey of recovery?

This session focuses on three ways you can support your veteran’s recovery, namely:

1. Noticing and celebrating his/her strengths
2. Setting short-term goals and working together
3. Facilitating teamwork among the veteran, professionals, and family
I. Identifying and celebrating your loved one’s strengths

Historically, the mental health field has spent a lot of energy focusing on people’s problems, symptoms, and difficulties. Entire diagnostic systems have been created to describe, diagnose and treat emotional problems. Until recently, the arena of personal strengths and character has been relatively neglected. Paying attention to someone’s talents and positive qualities can help him/her get the most out of treatment and improve his/her sense of self-worth.

The old saying, “You find what you look for,” applies here. If you’re irritated or annoyed with your family member, it’s easy to find fault, isn’t it? What are the consequences of this focus on problems/failures? Unfortunately, all too often they are relationship conflict, low self-esteem, and decreased willingness to try new things.

However, when we pay attention to and celebrate others’ strengths, relationships can blossom; and people can take pride in themselves and their accomplishments. Just as with parenting, we encourage you to “catch your family member being good,” and ignore the small issues that aren’t worth the conflict.

A new movement in mental health termed Positive Psychology (e.g., Peterson & Seligman, 2004; Seligman, 2006) has turned our focus to “that which is good” in people…let’s do that now.

Activity:
1. Please take out a sheet of paper and make a list of at least five qualities or strengths of your loved one. (Facilitator may choose to distribute Handout CC: Character Strengths to help participants reflect on these qualities in veteran).
2. Next, describe a situation or example that demonstrates each of the strengths.
3. How do you feel when you see these qualities/behaviors in your veteran?
4. How often do you tell him/her that you notice these qualities? What these strengths mean to you?
5. As homework, we encourage you to “catch” your loved one demonstrating at least one of these qualities/strengths this week, and to compliment him/her on that specific situation. It’s important to learn how to be an enthusiastic encourager. We predict that your family member will really like it, and it will probably feel good for you to do as well.

Not sure what/how to say it? Here are some suggestions:

To recognize his/her sense of humor, you could say:
- “Even in stressful situations, you always keep me laughing. I appreciate that.”
- “You have such a gift at telling funny jokes.”
To celebrate your family member’s efforts or progress, you may wish to say:
- “I’m really proud of you for (fill in the blank).”
- "Way to go - look at how much you got done."
- "Looks like you put a lot of work into that."
- "It took a lot of courage for you to do that (specify what he/she did)."

To express your appreciation, the following phrases may be useful:
- "Thanks – that helped a lot."
- "I really appreciated your help; it made my job a lot easier."
- "We really needed help, and you had just what we needed to get the job done. Thanks."

If your family member is demonstrating courage by trying something new, you may consider simple comments such as:
- “You can handle it."
- "I know you'll do fine."  
- "You'll make it through."

Modified from Dick and Betsy Greer, Family Reference Book of AMI-Van Nuys (http://www.schizophrenia.com/family/60tip.html)

II. Setting realistic goals

Sometimes consumers struggle with a sense of purpose. As seen in the above definition of recovery, it’s important for all people to have a sense of meaning in their lives. This struggle can be compounded when consumers are unable to work outside the home; many become isolated and spend much of their time sleeping, watching television, or playing on the computer. They wonder what they are contributing to the family or their community. These negative thoughts can increase their level of depression and decrease their motivation to make positive changes.

As a family member you can be extremely helpful by talking with your veteran about short-term goals. For example, perhaps he/she has always wanted to get involved with photography or has thought about joining a church or wants more friends.

When considering possible goals, select goals that have a good chance of success and offer a sense of hope. For example, if your loved one hates public speaking, you probably wouldn’t encourage him/her to volunteer as a speaker for the NAMI In Our Own Voice program (a wonderful program in which consumers provide workshops to share their personal stories about living with mental illness to teach others about recovery). However, you might encourage him/her to consider volunteering at the local animal shelter, which would be less anxiety provoking and could provide pleasant opportunities for playing with animals.
In setting these goals, it’s important to have small, measurable steps that demonstrate progress. For example, if your husband wants to take up photography as a hobby, you could together brainstorm steps such as: (ask the participants to brainstorm a list such as this):

1. Checking out library books on photography and equipment
2. Going to a store to look at cameras
3. Talking to others who know about photography
4. Exploring online options for purchasing a camera
5. Considering your budget and/or saving money for a camera
6. Calling the VA hospital or local community center to explore local photography classes
7. Asking your friends if they have a camera you could borrow

As your veteran takes these small steps, it’s essential that you celebrate each accomplishment. Remember to acknowledge the effort involved, regardless of the outcome. For example, perhaps he/she called the local VA hospital to ask about classes but wasn’t able to get any information because the therapeutic recreation department was closed for the day. You’d still want to praise him/her for making the call and define a plan for the next step.

Similarly, creating a regular schedule/routine can make a big difference in your loved one’s life. Encouraging him/her to volunteer in some capacity or consider a regular exercise schedule can provide much-needed structure. As we tell veterans, “The bed is not your friend when you’re depressed!” Helping your loved one create a weekly calendar with scheduled activities can give him/her something to look forward to as well.

In encouraging your loved one to move toward goals and create a regular routine, an encouraging approach works best. However, it’s often a fine balance between providing encouragement and nagging! Remember that your loved one is “in the driver’s seat” in his/her recovery.

III. Communicating with providers

The third topic in today’s session about supporting your loved one on the journey of recovery pertains to creating and maintaining strong, open relationships with mental health providers. This ability is truly a skill, and having good working relationships can be very beneficial – for your veteran and yourself.

As a family member, you are a very valuable part of the treatment team. The information you have about the consumer’s functioning is important to providers. Although you may struggle with access to doctors and experience frustration regarding issues of confidentiality, professionals can benefit from your observations of your loved one. You obviously have much more contact with him/her than the providers do. Therefore, you can notice “red flags” and communicate this information earlier.
Note to facilitator: Depending on needs of participants, you may wish to review the “red flag” information from Session 8, “Creating a Low-Stress Environment and Minimizing Crises.”

A. Here are some suggestions on how to effectively interact with professionals:

1. Remember that providers are extremely busy. Be brief and concise. Avoid overwhelming them with details or long stories.
2. Sometimes both consumers and families forget what they want to tell or ask the doctor, and they may feel rushed during brief appointments. Therefore, it’s important to be prepared. Bring in a list of specific questions.

**Discussion Question:** What are some typical questions you might want to ask?

Possible questions might include:

- What is the diagnosis?
- What is likely to happen in the future?
- What is this medication for? How will it help?
- What possible side-effects should we be aware of?
- Who should we contact if we’re concerned about something regarding his/her emotional well-being?
- Who do we call in case of an emergency (both during the workday and after hours)?
- What other treatment options are available?

3. Bring a pad of paper so you can take notes when the provider shares important information. Feel free to ask him/her to write down specific information such as the diagnosis and medications. You may also ask for informational pamphlets/handouts/websites regarding your loved one’s illness and treatment options.

4. Be prepared to give the provider an update on the consumer’s functioning.

*Distribute Handout DD: My Perception of My Family Member’s Current Functioning.*

This form is a potential tool to aid in communicating with the provider. If organizing your concerns before the appointment is helpful, you can work with your loved one to review his/her functioning in several domains. If you cannot be present at the appointment, you may choose to send this form to the doctor before your loved one’s appointment.

*Distribute Handout EE: Log of Mental Health Treatment.*
As episodes of mental illness can be cyclical and consumers may take many different medications over the course of the illness, the psychiatric history can become extensive and complicated. Consumers are encouraged to keep records of their treatment experiences and medication regimen. However, this task can be overwhelming; and consumers may be unable to keep an accurate log. Therefore, you may choose to keep a log of the symptoms you observe, the efficacy and side-effects of various medications, his/her hospitalizations, etc. Be sure to include any over-the-counter medications and/or herbal supplements (e.g., St. John’s Wort) he/she is taking.

5. If your family member agrees, you may wish to have him/her sign a release-of-information form allowing the provider to speak openly with you. If your family member refuses, you can still convey your concerns to the doctors (e.g., calling them on the telephone, leaving a message, writing a letter). Most providers really want to hear your perspective and observations, as your input can be very helpful in providing the best care for your family member. However, the doctor cannot tell you any specific information about your loved one without a signed release.
Character Strengths

Creativity: Thinking of novel and productive ways to conceptualize and do things

Curiosity/openness to experience: Taking an interest in ongoing experiences for their own sake; exploring and discovering

Love of learning: Mastering new skills, topics and ideas

Bravery: Not shrinking from threat, challenge, difficulty, or pain; acting on convictions even if unpopular

Persistence: Finishing what one starts; persisting in a course of action in spite of obstacles

Integrity/honesty: Being genuine; taking responsibility for one’s feelings and actions

Vitality/enthusiasm: Approaching life with excitement and energy

Love: Valuing close relations with others

Kindness/generosity/compassion: Doing favors and good deeds for others

Citizenship/teamwork: Being loyal and working well as a member of a group or team

Fairness: Treating all people the same according to notions of fairness and justice

Forgiveness and mercy: Forgiving those who have done wrong; accepting the shortcomings of others; giving people a second chance

Gratitude: Being aware of and thankful for the good things that happen; taking time to express thanks

Humor/playfulness: Liking to laugh and tease; bringing smiles to other people

Spirituality/sense of purpose: Having coherent beliefs about a higher purpose, the meaning of life, and the meaning of the universe

My Perception
of My Family Member’s Current Functioning

His/her name: ____________________________
Form completed by: ____________________________
Your relationship to individual: ____________________________
Date: ____________________________

Specific concerns I have about my family member:
1. 
2. 
3. 

Major family or life events that could be affecting his/her mental health:

Overall, I think my family member’s current mental health is: (circle one)
Better than usual  About normal for him/her in past 2 years  A little worse than usual  The worst he/she has been in past 2 years

My impression of his/her:
A. Compliance with medications (is he/she taking them as prescribed?):
B. Current sleeping habits (# of hours/night, naps):
C. Current use of alcohol or other drugs:
D. Daily activities:

Questions I have for the doctor:
1. 
2. 
3.
Log of Mental Health Treatment

His/her name: 
Form completed by: 
Relationship to him/her: 
Date: 

Psychiatric Medications (including any over-the-counter medications and/or herbal supplements)

<table>
<thead>
<tr>
<th>Dates that consumer took medication</th>
<th>Name of the medication</th>
<th>Dosage</th>
<th>Doctor</th>
<th>What symptoms did the drug help?</th>
<th>Side-effects</th>
<th>Was it taken as prescribed?</th>
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</thead>
<tbody>
<tr>
<td>1/99 – present</td>
<td>Zoloft</td>
<td>100mg</td>
<td>Masters</td>
<td>↑ mood, ↓ crying, slept better</td>
<td>some headaches, but went away</td>
<td>95% of the time</td>
</tr>
</tbody>
</table>

Support And Family Education:
Mental Health Facts for Families
Michelle D. Sherman, Ph.D
### Psychiatric Admissions/Substance-Abuse Treatment Programs

<table>
<thead>
<tr>
<th>Dates</th>
<th>Name of hospital</th>
<th>Doctor</th>
<th>Reason for admission</th>
<th>Diagnosis(es)</th>
</tr>
</thead>
<tbody>
<tr>
<td>3/5/00 – 3/15/00</td>
<td>OKC VA Medical Center</td>
<td>Warren</td>
<td>thoughts of killing himself after his dad’s death</td>
<td>Major Depressive Disorder</td>
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<tr>
<td>1/90 – 2/90</td>
<td>St. Anthony’s Hospital</td>
<td>Harding</td>
<td>heavy alcohol use &amp; a 2nd DUI</td>
<td>Alcohol Abuse, Depression</td>
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</table>

### Psychotherapy or Classes

<table>
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<th>Type of service</th>
<th>Provider (credentials)</th>
<th>Frequency</th>
<th>Issues addressed</th>
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</thead>
<tbody>
<tr>
<td>6/99 - 8/99</td>
<td>Depression Class</td>
<td>Morgan, Ph.D.</td>
<td>once/week</td>
<td>changing negative thought patterns</td>
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### Consumer’s Current Physical Health Problems

Support And Family Education:
Mental Health Facts for Families
Michelle D. Sherman, Ph.D
Session Seventeen - What We Tell Our Children and Other People About Mental Illness

Materials Needed:
Handout FF: What Should We Tell Family Members and Friends?

I. What to tell our children, friends, and other family members about our loved one’s mental illness

A. Making decisions about how much and when to tell others about your loved one’s mental illness can be challenging. Families may face this struggle in many different situations.

Discussion Questions:

- Does anyone wish to share experiences of being uncertain of what to say?
- What have been awkward or uncomfortable situations for you?
  - How have you handled these situations?
  - How did you feel?

B. The discomfort experienced by family members only compounds this challenge of knowing what to say. As discussed in previous sessions, the following emotions are quite common in families:

<table>
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<tr>
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C. Families may also want to share feelings of pride in their loved one’s courage in facing the illness. Family members report gaining compassion for human suffering through their experiences of living with mental illness in the family.

D. This workshop will begin by discussing issues dealing with children. Some of you may not have children – or your children may be grown – but, hopefully, these issues will be relevant, perhaps even to your grandchildren. Please feel free to offer tips on how you’ve dealt with your children during our discussion.

II. How children may respond to mental illness in the family

A. Children may distance themselves emotionally and act as if they do not care about the parent. This style does not mean that the children are not affected; rather, detaching may be their means of coping with the stressful situation (Woolis, 1992).

1. Children often fear becoming ill themselves. They wonder if they can “catch” the illness.
2. Older children may worry about their own children inheriting the illness.

B. Having a parent with a mental illness can be experienced as a loss for children.

1. Children may sense they have a parent “who is there (physically) but not there (emotionally).”
2. Sometimes children feel abandoned and alienated from the family.
3. This situation can lead to separation anxiety. Because the parent is withdrawn and inaccessible, the young person may cling even more tightly to the parent and struggle with developmental issues of autonomy and independence.
4. When much of the family’s attention is focused on the parent rather than the child, the young person may be more likely to engage in disruptive behaviors (as negative attention can be perceived as better than no attention at all).

C. Children may adopt a variety of different roles in response to parental mental illness:

| caretaker | escapee |
| baby     | recluse |
| mourner  | good child |
| patient  | bad child |

1. Although these roles can be adaptive, being stuck in them can interfere with normal development and individuation from the family unit.
2. It is important to “allow children to be children,” rather than having inordinate responsibilities (e.g., excessive caretaking of other children, doing all the household chores, managing the consumer’s unruly behavior).

III. How we can help the children

Optional: Show and discuss a video clip such as:

Canvas, The Film (Marcia Gay Harden as a mother living with schizophrenia and how this affects her husband and 12-year-old son)

I Love You Like Crazy: Being a Parent with Mental Illness by Mental Illness Education Project Videos, www.miepvideos.org


Tarnation (2003).

About A Boy (2002). Impact of maternal depression and suicide attempt on her son

Explain resources created specifically for young people:

FOR YOUNG CHILDREN:


FOR TEENAGERS:


A. Recognize that several time periods can be especially difficult for children (Woolis, 1992):

1. At the onset of the mental illness.
   
   a. What are these confusing behaviors or symptoms?
      “Why does Daddy sleep all day long and stay up all night?”
   
   b. What’s going on in my family?
      “Why doesn’t Mom come to my basketball games anymore?”
   
   c. Will it go away? If so, when?
      “When will Dad be like he used to be and read to me at bedtime?”

2. During adolescence.

   a. Appearances and “fitting in” are very important during this developmental period.
   
   b. Youth may be afraid and embarrassed about peers’ opinions and judgments about them and their family.

3. During times when the parent is acutely ill and/or acts in bizarre, unusual or socially unacceptable ways.

   Children often experience these times as especially frightening and embarrassing.

B. Talk to your children about the illness and how it affects everyone in the family. (Sturges, 1978)

1. Children need answers to “What is it? Will I get it? Will my parent get better?”
2. Parents need to acknowledge that we don’t have all the answers about the consumer’s illness. However, the child can learn ways to be helpful and cope effectively.
3. Children are especially confused when parents deny the existence of the mental illness or don’t talk about it. Even if the parent is trying to protect the children, youth may feel quite resentful, even years later.

C. Be honest with your children. Children should not be promised that the parent will get well and stay well forever.
D. Tell your children that that they are not to blame – they didn’t do anything wrong!
   In children’s naive and simplistic view of the world, they sometimes think they did
   something wrong and may have caused their parent to be sick.

E. Learn about the illness, especially about the possibility for it to be transmitted to
   them or to their children.

F. Try to instil a sense of being loved by the parent with the illness (even when the
   consumer behaves in rejecting ways that can be quite confusing and hurtful to the
   child).

G. Foster a strong relationship between the child and healthy adults and/or adolescents
   in the family.

H. Foster supportive relationships between the children and people outside the
   immediate family. Activities outside the family and a good support system of
   friends can serve as buffers for children.

I. Educate your child (at a developmentally appropriate level) about the stigma and
   inaccurate perceptions that many people hold about mental illness. Never use
   derogatory terms (e.g., “crazy”) to describe individuals with mental illness, and
   correct your children if they do so.

J. To learn more about supporting children who have a parent living with mental
   illness, participants may wish to explore these websites. Many wonderful programs
   are active in Australia and the United Kingdom:

   COMIC: Children of Mentally Ill Consumers [http://www/howstat.com/comic/]

   COPMI: Children of Parents with a Mental Illness [www.copmi.net.au]

   Helping Children Understand Mental Illness: A Resource for Parents and Guardians (A
   project of the Mental Health Association of Southeastern Pennsylvania)
   [http://www.mhasp.org/coping/guardians.html]

IV. Dealing with other family members and friends

A. Awkward, challenging moments can arise in interactions with other family members and friends. Especially when caught off guard, you may struggle with knowing what to say.

B. Some families exert a great deal of energy trying to hide the existence of the mental illness from other people. Families may lie about the consumer’s activities or whereabouts (e.g., “Uncle Jimmy is living in Europe for the summer”), may discourage others from coming to the family home, and can keep the consumer quite distant from his/her social network. Family members may spend a lot of energy maintaining the secrecy and lies, and the social isolation can be quite damaging for all family members.

C. To be most helpful, you may choose to discuss in advance with your family member how the two of you would like to respond to inquiries, etc. Communication and planning can reduce the potential for hurt feelings later.

D. Different situations call for diverse responses from family members. The context and individuals involved may influence your response. For example, if your loved one acts bizarrely in public (e.g., starts talking about the special messages he’s receiving from the television program), you have several choices:

1. If the listeners are not important to you (e.g., waitress, gas station attendant) or if the timing is bad, you can ignore the bizarre behavior or not say anything at all. You can also simply say that your relative is having a hard time, and you don’t wish to discuss it. You don’t owe strangers an explanation.

2. If the listener is important to you, you can choose to educate him/her. You can share a limited amount or disclose more, depending on the situation. The key is to always be respectful and determine in advance what works best for your family.

V. What we might choose to tell family members and friends

*Distribute Handout FF: What Should We Tell Family Members and Friends? (parts adapted from Woolis, 1992)*

A. These facts can educate people about mental illness and challenge some stereotypes and myths. Given the media’s often sensationalized and inaccurate portrayal of mental illness, people may hold incorrect beliefs about its nature.
1. Although the exact causes of mental illness are not yet known, many illnesses have a strong biological/genetic component.

2. Mental illness is very common. According to the National Institute on Mental Health, about one in four or five adults has a diagnosable mental disorder in a given year. That’s over 58 million people in the United States!

3. According to the National Alliance on Mental Illness, 1 in 17 Americans has a serious mental illness (www.nami.org). That’s over 6 million Americans.

4. Mental illness affects thinking, behavior, feeling and judgment.

5. The course of mental illness is often unpredictable, as symptoms can come and go for no apparent reason.

6. There are no known cures or easy ways to prevent mental illness – but doctors can help some symptoms with medications and therapies. The side-effects of some medications can be unpleasant.

7. Mental illness can be quite severe and chronic. It often has a strong impact, both emotionally and financially, on the person with the illness and those close to him/her. Therefore, these people need a great deal of support and understanding.

8. Mental illness is not contagious.

9. Individuals with mental illness are rarely dangerous; rather, they generally tend to fear people and be quite introverted.

B. People can better understand the nature of mental illness by comparing it to cancer or diabetes. Many points on this handout apply equally to mental and physical illnesses. This explanation also gives people a better idea of how to support you.

Because concerned friends or extended family members often do not know what to do, they may choose to do nothing, which can be very painful for the family. For example, Carol Grogan was quoted in Wasow (1995) as saying: “You couldn’t conceive of a situation in which a relative wouldn’t call you if your wife had severe diabetes. But if it’s mental illness, forget it. No calls, no casseroles, nothing” (p. 61).

C. People usually follow your lead regarding how much and what to say about your family member. Don’t expect others to bring the subject up if you never do. It’s helpful to assume that others want to be sensitive, but they are uncomfortable and do not know how to support you.
1. Family members may feel hurt by others who do not say anything – or by people who try to be helpful but do or say the wrong thing. Research has documented that family members feel more depressed and distressed when other people deny the mental illness, avoid the family, or make critical and intrusive comments (Rauktis, Koeske & Tereshko, 1995).

2. So families need to tell others how they can be supportive. You need to tell them if it’s helpful to ask you questions, listen to you, give you advice, spend time with your relative, etc.

D. Remember the limitations on how much you can change others’ views and perceptions. Showing respect for how others are dealing with the situation is essential (even when it may be difficult). No matter how much people may try to distance themselves, they cannot escape the impact entirely. Each person’s path and pace are unique, and the impact of the mental illness may differ across relationships (e.g., parent vs. child vs. sibling vs. spouse, etc.).

E. Human beings fear what they do not know or understand. Providing others with information helps them to feel more comfortable, which in turn will help them interact more effectively with your loved one. You may wish to share the following suggestions with concerned individuals:

1. Remember that, first and foremost, people living with mental illness are human beings with needs and feelings like everyone else. Therefore, treat them with respect, even if their behavior may be confusing. When they are present, avoid talking about them as if they are not there.

2. Make efforts to compliment and praise the individual whenever you find an opportunity. Focusing on the positive can help his/her self-esteem and strengthen your relationship.

3. Avoid overwhelming someone with questions about him-/herself or his/her illness.

4. Avoid telling him/her what to do (unless he/she asks for advice or is in a dangerous situation).

5. Attempt to maintain a calm manner when you are with him/her, as he/she may be hypersensitive and over-react to emotional ups and downs.
What Should We Tell Family Members and Friends?

As much or as little as you want!

If you want others to better understand mental illness, the following information can be helpful:

1. Although the exact causes of mental illness are not yet known, many illnesses have a strong biological/genetic component.
2. Mental illness is very common! Over 6 million Americans have a serious mental illness.
3. Mental illness affects thinking, behavior, feeling and judgment.
4. The course of mental illness is often unpredictable, as symptoms can come and go for no apparent reason.
5. There are no known cures or easy ways to prevent mental illness – but doctors can help some symptoms with medications and therapies. The side-effects of some medications can be unpleasant.
6. Mental illness can be quite severe and chronic. It often has a strong impact, both emotionally and financially, on the ill person and those close to him/her. Therefore, these people need a great deal of support and understanding.
7. Mental illness is not contagious.
8. Individuals with mental illness are rarely dangerous; rather, they generally tend to fear people and be quite introverted.

What Should We Tell the Children?

1. You are not to blame – you didn’t do anything wrong!
2. We don’t have all the answers, but we can deal with this situation together. You can be helpful to your parent – and here’s how…. (give specific behaviors children can do).
3. Both parents love you and will be here for you to the best of our abilities.
4. It’s ok to ask questions.
5. Please tell us how you feel.
6. Answer questions (at an age-appropriate level) about the illness, such as, “What is it? Will I get it? Will my parent get better? What are the risks that my children may get it some day?”
7. Foster supportive relationships for the child with people outside the immediate family. It’s important for the child to have a good support system of friends and other activities outside the family.
8. Children should not be promised that the parent will get well and stay well forever.

Parts adapted from *When Someone You Love Has a Mental Illness* by R. Woolis (1992)
Helpful Resources for Youth

FOR YOUNG CHILDREN:


FOR TEENAGERS:


To learn more about supporting children with a parent living with mental illness, you may wish to explore these websites. Many wonderful programs are active in Australia and the United Kingdom:

COMIC: Children of Mentally Ill Consumers http://www.howstat.com/comic/
COPMI: Children of Parents with a Mental Illness www.copmi.net.au
Helping Children Understand Mental Illness: A Resource for Parents and Guardians (A project of the Mental Health Association of Southeastern Pennsylvania) http://www.mhasp.org/coping/guardians.html

Support And Family Education:
Mental Health Facts for Families
Michelle D. Sherman, Ph.D.
Session Eighteen – Dealing with the Stigma Surrounding Mental Illness

Materials Needed
Handout GG: Coping with Stigma

I. Introduction: Experiential exercise

Invite participants to participate in an experiential exercise. Ask the following questions sequentially:

Raise your hand if:

1. You went to a doctor’s appointment in the past year.

2. You were admitted to a hospital for any reason over the past year.

3. You took any medication over the past year.

How did it feel to answer these questions in this group setting?

Now if we were to ask you to raise your hand (no need to raise your hand) if...

1. You saw a mental health professional over the past year.

2. You took any psychiatric medications over the past year.

... how would you feel?
Discussion Questions:

- How are these questions different from the previous ones? What makes them different?

- How does this activity relate to your loved one’s experience of having a mental illness?

II. Impact of stigma on family experience of mental illness

Discussion Questions:

- What is the biggest consequence for your family of your loved one’s having a mental illness?

- How long did it take your loved one to seek mental health treatment once the need became apparent?

- What kept him/her from seeking treatment earlier?

- What motivated him/her to seek treatment?

A. *Stigma* has been defined as a mark, blemish or defect; a symbol of disgrace, shame, or reproach. Stigma is often used to differentiate people. It often involves fear of that which is different.

1. What does *stigma* mean to you?

2. How has stigma affected your family?

   Possible answers may include:
   - Embarrassment/social discomfort
   - Feeling “different”
   - Decreased self-esteem in loved one
   - Isolation
   - Problems in loved one’s getting/maintaining employment
   - Challenges in getting housing
   - Insurance issues
   - Others?
B. Stigma can deter individuals from seeking treatment. For example,

1. According to the National Institute on Mental Health, about one in four or five adults has a diagnosable mental disorder in a given year. That’s over 58 million people in the United States.

2. Yet only about half of all Americans with a serious mental illness seek treatment (Kessler et al., 2001).

Although failure to seek mental health treatment can be attributed to a variety of factors (e.g., lack of money/insurance, availability of providers), mental health stigma is also a significant deterrent.

Discussion Questions: How do you think stigma is perpetuated?

Possible answers may include:
- Portrayals of individuals with mental illness in the media as violent and unable to contribute to society
- Fear of that which is different
- Avoidance of individuals with mental illness
- Messages given to young people about mental illness

III. Understanding the history of stigma in mental health

A. Unfortunately, the mental health profession contributes to the stigma surrounding mental illness. For example, as recently as the 1960s and 70s, mental health professionals were taught that schizophrenia was caused by being raised by a cold, unavailable, critical “schizophrenic mother” and living in a family marked by high expressed emotion, which involves much criticism, hostility, and emotional over-involvement. Families were held responsible for the loved one’s mental illness.

B. These theories guided our understanding of mental illness and psychiatric care, and the mental health profession harshly judged many families. Unfortunately, this viewpoint contributed to the stigma and sense of responsibility that many families experienced.

C. Since that time, science has reformulated our theories regarding the cause of mental illness, resulting in a fairly widespread acceptance of the vulnerability-stress model (as explained in session one) of etiology.

1. As a review, the vulnerability-stress model involves understanding mental illness as being caused by a combination of “nature” (genes, heredity, etc.) and “nurture” (family upbringing, life events, social environment, etc.).
2. Individuals may inherit a predisposition to mental illness and then experience a stressor that results in the emergence of an illness. On the other hand, an individual may be born with a predisposition but have excellent coping strategies and/or social support and never experience the illness.

3. Research continues to explore the relative contributions of genetics and life experiences to various mental illnesses. For example, some illnesses (e.g., schizophrenia) are believed to be highly influenced by genetics; while others (e.g., PTSD) are more a response to life events/situations.

D. In spite of science’s shift away from a “family-blaming” mentality, many families continue to feel responsible for their loved ones’ illnesses. Perhaps in response to this experience and in an attempt to relieve years of guilt, many families and advocacy organizations have adopted an extreme “nature” viewpoint; this perspective conceptualizes mental illnesses as “neurobiological disorders” and minimizes the role of any social/family contribution.

E. Similarly, there is growing attention to means of overcoming stigma evidenced by research, practice recommendations, and reports urging the profession to tackle this challenging topic. For example, the President's New Freedom Commission on Mental Health report, *Achieving the Promise: Transforming Mental Health Care in America*, includes a recommendation to “Advance and implement a national campaign to reduce the stigma of seeking care” (Recommendation 1.1). In a parallel vein, mental health providers have recognized the role that stigma places in deterring service members from seeking mental health help (both while on active duty and thereafter) (Hoge, Castro, Messer et al., 2004), and many new programs are attempting to make our services more accessible.

IV. The role of diagnosis in stigma

A. Psychiatry has devoted years of research and clinical study to identifying and naming clusters of behaviors/problems as specific disorders. When classification systems emerge, researchers can study the clinical phenomena and develop effective treatments. The *Diagnostic and Statistical Manual of Mental Disorders* (currently in its 4th revision) contains specific criteria sets for many psychiatric diagnoses.

B. Labels can also provide a useful, normalizing function for the consumer and family. Individuals often feel reassured when diagnosed with a condition because they know they’re not alone and feel more understood.

C. However, labels/diagnoses can have negative consequences as well:
Discussion Question: How can diagnoses or labels reinforce stigma?

Possible answers may include:

1. Diagnoses are sometimes misused when a unique individual is placed into a general category (e.g., “He’s just a schizophrenic”), and his/her experience is oversimplified. Further, expectations are sometimes lowered because of the label (“...he wouldn’t be able to hold a job”).

2. Diagnoses (even if inaccurate) often stay with a person for a long time. For example, documentation in medical records of psychiatric and/or substance-abuse problems can interfere with consumers’ abilities to get insurance coverage and other treatments in the future.

3. Diagnoses can serve as a rationalization for behavior (e.g., “Don’t hold me responsible because I am sick”).

Optional: Share a video clip depicting issues surrounding stigma.

Suggested videos (most contain discussion questions as part of the videotape package):


*Imagining Robert: My Brother, Madness and Survival.* (2002). Films for the Humanities and Sciences. 56 minutes. Study guide and other resources available on-line at: www.imaginingrobert.org


*In Our Own Voice.* (2001). Idaho Public Television. 60 minutes.

*A Beautiful Mind* (2001). Depicts the true story of John Nash (a brilliant mathematician who has schizophrenia) and debunks some negative public stereotypes of mental illness.

V. Coping with stigma

Stigma can seem overwhelming at times, and changing societal attitudes may feel like a daunting task. However, families can take specific steps to help cope with the stigma in their specific situations/communities.
A. Remember that you and your loved ones have choices.

1. You can decide whom to tell about the mental illness and what to tell them. Your choice may range from telling no one at all to telling anyone (e.g., via public action).

2. Your decisions may change over time and likely depend on the specific relationship.

3. You and your loved one may disagree on whom and what to tell. In general, families are well served by respecting the consumer’s decisions about sharing this information. However, family members need places where they can be honest and receive support, either professionally (e.g., support groups) or personally (through family and friends). When differences among families emerge, you may use the problem-solving strategies outlined in session 7.

4. You and your loved ones may choose to do a cost-benefit analysis surrounding these decisions:

**Group Activity:** *Invite participants to create a list of pros and cons of disclosing the mental illness* (adapted from Corrigan and Lundin, 2001). *List them in a chart or worksheet, and facilitate discussion surrounding benefits and costs of disclosure.*

**Potential Benefits of Disclosing**

**Possible answers may include:**

- You don’t have to worry about hiding the mental illness and/or explaining confusing behavior to others.
- You don’t have to spend as much energy keeping a secret.
- You can release some shame about the illness in the family.
- Others may be able to provide additional support.
- Others may be coping with similar situations, and you can provide mutual support. You could feel less alone.

**Potential Drawbacks of Disclosing**

**Possible answers may include:**

- You take the risk of being vulnerable. Others can say unkind things to or about your loved one/family.
- Your loved one and/or family might be excluded from social activities.
- Your loved one may experience discrimination (housing, work, etc.).
- Having shared the information, you may worry more about what others think of your family.

**Distribute Handout GG: Dealing with Stigma.** Although we did this activity today as a group, you may wish to sit down with your loved one and create a list of pros and cons for your unique situation.

B. Remember that you are not alone.

1. Many people struggle with depression, anxiety, substance abuse, and other mental illnesses. In fact, research has revealed that one in four Americans will experience a serious mental illness at some point during the course of his or her life.
2. Many famous individuals have disclosed their mental health struggles, and some celebrities have used their status to educate the public about mental illness:
   a. Individuals who have disclosed depression: Robert Boorstin (White House aide, bipolar disorder), Mariah Carey, Charles Dickens, Tipper Gore (after son’s car accident), Amy Grant, Abraham Lincoln, Rosie O’Donnell, Oprah Winfrey, Rod Steiger, Mike Wallace, Tennessee Williams, Monica Seles, Elton John, James Taylor, Robin Williams
   b. Individuals who have disclosed substance abuse: AJ McLean (Backstreet Boys); Ben Affleck; Aaron Sorkin (creator of “West Wing”); Matthew Perry (“Friends”); Robert Downey, Jr.; and Martin Sheen

C. Remain hopeful and remember that treatment works.

1. Science has made tremendous progress in the past few decades in understanding mental illness and discovering effective treatments. New medications and psychosocial treatments are being created, and many individuals enjoy productive lives.
2. You can play an active role in your loved one’s treatment plan by communicating regularly with providers, encouraging your loved one to take medications and participate in therapies, maintaining a low-stress family environment, and watching for relapse warning signs.

D. Praise your loved one for seeking help.

1. Mental health treatment can be difficult, as individuals often need to be patient in trying new medications, coping with side-effects, and learning new behaviors. Therefore, helping your loved one to feel good about him/herself is important.
2. Your praise can do wonders to lift your loved one’s spirits, so remember to tell him/her often that you are proud of him/her.

3. The times that you feel least motivated to give praise are the times when your loved one probably needs your support the most! Be honest, but look for something to praise in your loved one.

E. Stay active and surround yourself with people who are supportive.

1. One potential negative consequence of stigma can be social isolation. When you fear others’ judgment and ridicule, you understandably want to avoid them.

2. However, isolating and discontinuing enjoyable activities put you at high risk for depression and burnout. So take a risk and try new activities in your community. You may choose to investigate the local chapter of NAMI (www.nami.org) or a volunteer organization.

3. Sometimes other people don’t know what to say or how to support you. Therefore, telling your friends/family members how they can be helpful to your family can be important. Expressing your requests specifically and directly (e.g., “I would really appreciate if you would…”) is most effective.

4. Consider advocacy efforts and speaking out against stigma. You can advocate either on a small or large scale.

   a. In your daily interactions with others, you can address misconceptions by gently sharing accurate information and/or your personal experiences.

   b. If you prefer larger-scale action, you may consider lobbying for mental health parity, writing editorials for the newspaper, responding to stigmatizing material in the media, writing your state representative about specific mental health bills, and/or participating in NAMI advocacy activities.

? Discussion Question:
- If there was one message you could give the public about mental illness, what would it be?
Dealing with Stigma

Coping with stigma

1. Remember that you and your loved one have choices. You can decide whom to tell about the mental illness and what to tell them.

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2. Remember that you are not alone.

3. Retain hope and remember that treatment works.

4. Praise your loved one for seeking help.

5. Stay active and associate with people who are supportive.

6. Consider advocacy efforts, such as getting involved with NAMI (1-800-950-NAMI or www.nami.org).

Support And Family Education:
Mental Health Facts for Families
Michelle D. Sherman, Ph.D.
Program Satisfaction

The extent to which this program meets the participants’ needs is assessed on an ongoing basis. Modifications are made to the program based on participants’ feedback.

Attendance

The number of participants in attendance in the first 8 years of the program ranged from 4 to 25, with an average of 10-12 people per session in recent months. Some family members attend every session, but others attend when their schedule permits or when they are especially interested in the session topic. Some participants live several hours away, so transportation and weather conditions have also been important factors. Some family members have anecdotally reported that their loved ones have discouraged them from attending the program because of paranoia or other fears. As awareness of the program has increased, the number of participants has grown considerably.

Development of Group Cohesion

Even though the program meets once a month and participants differ each session, group cohesion develops quickly among family members. Participants freely provide support to one another during sessions, and some have exchanged telephone numbers and met socially outside the group. Given the sense of isolation that many family members feel, they likely bond quickly to one another out of shared experiences and high levels of need for identification and support.

Response from Providers

Providers have responded very well to the availability of the program, and the referral base has expanded to include many different units across the medical center. Several providers have expressed the sentiment that “We should have had this program a long time ago,” given the high level of needs of these family members. Many providers have endorsed the program and indicated that the family members who attend the SAFE Program are more involved in their loved one’s care, as evidenced by attending appointments with their loved one and calling the provider when problems arise.

Heterogeneity of Mental Illnesses

A significant question in the development of this program was whether sessions should focus on a specific mental illness or address mental illness more generally. Given the similar needs among family members, the bulk of this program is geared to dealing with mental illness in general (although two sessions focus on the specific diagnoses of PTSD and schizophrenia). This format has worked well, as family members with quite different backgrounds are able to apply the general didactic material to their specific situation and learn from one another. Participants are reminded that each person’s situation is unique and has its own set of challenges.
Satisfaction Questionnaire

At the end of each session, participants complete an anonymous, brief satisfaction questionnaire (see Handout HH). The measure contains four five-point Likert scale items, one “check all that apply” item, and two open-ended qualitative items.

Based on over 8 years of data (March 1999 through October 2007) collected monthly at the Oklahoma City VAMC, the means for each five-point Likert scale item are (n = 875):

- Overall quality of presentation: 4.7
- Style of presenter: 4.7
- Relevance of topic: 4.6
- Amount of new information learned: 4.4

Overall mean (out of possible 20.0): 18.4

In response to the item about how the workshop has been helpful, the percentage of participants that indicated that the following needs were met (collapsed across all sessions) included (n = 685):

- Received handouts and a list of resources that apply to my situation: 92%
- Had opportunity to talk to other families who face similar issues: 83%
- Felt that my role as family is recognized and valued by the VAMC: 78%
- Had opportunity to ask doctors questions about mental illness: 75%
- Learned new ideas about how to help my family member: 74%
- Learned more about the treatments of mental illness: 70%
- Learned more about the definitions of mental illness: 69%
- Increased my awareness of various resources at the VAMC: 63%
- Learned more about the causes of mental illness: 61%
- Increased my awareness of community resources (e.g., NAMI): 45%
SAFE Program: Support And Family Education  
Mental Health Facts for Families

**Evaluation Form**

Please indicate your rating on each of the following items by circling the appropriate number on the scale:

**TOPIC:** PTSD and its Impact on the Family  
**DATE:** 6-12-00

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<td>1. Overall quality of workshop:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Style of presenter:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Relevance of this topic for you:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. How much new information did you gain from this workshop?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

5. How has this workshop helped you today? (Check as many as apply):

- [ ] Learned more about the definitions of mental illness
- [ ] Learned more about the causes of mental illness
- [ ] Learned more about the treatments of mental illness
- [ ] Had opportunity to ask doctors questions about mental illness
- [ ] Increased my awareness of various resources at the VA Medical Center
- [ ] Increased my awareness of resources in the community (e.g., NAMI)
- [ ] Had opportunity to talk to other families who face similar issues
- [ ] Learned new ideas about how to help my family member
- [ ] Felt that my role as family is recognized and valued by the VA Medical Center
- [ ] Received handouts and a list of resources that apply to my situation
- [ ] Other: ________________________________

6. How could this series be improved to better meet your needs?

7. Are there any specific topics that you'd like to see addressed in future workshops?

**Thank you!**

Support And Family Education:  
Mental Health Facts for Families  
Michelle D. Sherman, Ph.D.
Choosing an appropriate means of measuring the effectiveness of the SAFE Program was challenging. Similar programs have used a variety of different instruments to assess treatment outcome, including measures focusing on consumer variables and family variables. Many projects have incorporated multiple outcome measures. There is not a consensus regarding what variables are important to assess, and an instrument has yet to emerge as the accepted standard. Few psychometrically sound measures of coping behaviors, self-efficacy, or caregiving created specifically for family members exist (Schene et al., 1998; Solomon, 1996). Most measures are based on the concept of caregiver “burden,” a construct that is difficult to operationalize (Schene, Tessler, & Gamache, 1994). Further research is needed to clarify these assessment issues and enhance our ability to measure efficacy of family education and psychoeducational programs.

Across different programs, the variables chosen to assess changes in family functioning have been quite diverse. Some variables measured with family members have included:

1. Knowledge of mental illness
2. Level of expressed emotion in the family
3. Attitude toward mental illness
4. Attitude toward the consumer
5. Level of overall psychological distress of family member
6. Level of depression in family member
7. Level of anxiety in family member
8. Psychosomatic symptoms in family members
9. Level of caregiver burnout
10. Level of subjective burden on family member
11. Level of objective burden on family member
12. Additional financial burden on the family
13. Family member’s embarrassment
14. Consequences for the children and family
15. Family coping abilities
16. Grief/loss
17. Self-efficacy
18. Positive aspects of the family member’s role, including “rewarding personal experiences” and “good aspects of the relationship with the consumer”

Table One reviews specific measures that have been used to assess each of these variables. Other research projects that have used the measures are also listed. A recent excellent summary of outcome domains and assessment measures for family education and psychoeducation is also available (Cohen, Glynn, Murray-Swank, et al., 2008).
Summarizing the results of the numerous studies of family interventions is quite difficult. The diversity of programs, differing mental illnesses included in the projects, small sample sizes in many studies, and use of different outcome variables across projects render adequate comparisons difficult. Many studies also lack long-term follow-up data, so longitudinal research is badly needed in this area. Further, consumer variables (e.g., current functioning level, chronicity of the illness, gender, culture) likely interact with the ability of the family program to produce positive changes (Kazarian & Vanderheyden, 1992). For recent reviews of research on family interventions, please see McFarlane, 2002; Pfammatter, Junghan & Brenner, 2006; Pharaoh, Mari, Rathbone, & Wong, 2006.

None of the existing measures adequately and concisely addresses the goals that had been established for the SAFE Program (see p. 5 for review of goals). Consequently, a new measure, the SAFE Program Background Information Form (Handout II, p. 213), was developed. All participants complete this measure at the beginning of every workshop.

Demographic variables measured include consumer diagnosis, duration of consumer’s mental illness, relationship to the consumer, number of sessions attended, and amount of contact with the consumer.

As shown in Table Two, the most common consumer diagnosis has been PTSD, with over half of veterans having this diagnosis. About one in five families had a veteran living with major depression. The length of time that the individuals had been dealing with the mental illness was variable, ranging from a few weeks to over 30 years.

Over half the participants reported extensive (24-hours/day) contact with the consumer, which is consistent with the fact that almost half the participants were wives. Almost one third had either moderate (daily) or minimal (once every few days) contact.

As indicated, participants have been predominantly (80%) women and have included the roles of wife, girlfriend, mother, child, sibling, husband, friend, and others (e.g., grandparent, chaplain, sister-in-law, and daughter-in-law). In contrast to many similar family education programs through NAMI or other family organizations (e.g., Schene et al., 1998) in which a large majority of participants are parents, almost half of SAFE Program participants were spouses. This difference is likely due to the older age of the veteran population, which implicates less involvement by parents and a greater role for spouses and children. Over one quarter of participants were in their 60s or 70s, and one third were in their 50s.

In addition to demographics, the SAFE Program Background Information Form also assesses the following variables:

**Consumer’s Behavior:**

- Medication compliance in past 3 months
- Number of psychiatric admissions in past 2 years
- Percentage of mental health appointments consumer has attended in past 2 years
Family Member’s Experiences in Past 30 Days:

- Level of self-efficacy in caring for consumer
- Level of distress
- Knowledge of loved one’s mental illness
- Awareness of VA Medical Center resources
- Ability to engage in self-care activities

Preliminary evaluation of data collected in the first 3 years of the SAFE Program at the Oklahoma City VA Medical Center showed that program attendance was related to increased understanding of mental illness and enhanced awareness of VA resources. Workshop attendance is positively correlated with improvements in participants’ self-care (Sherman, 2003). Evaluation of 5-year data found that program attendance was positively correlated with understanding of mental illness, awareness of VA resources, and ability to engage in self-care activities – and inversely correlated with caregiver distress (Sherman, 2006).

Contact Information:

Michelle D. Sherman, Ph.D.
Director, Family Mental Health Program
921 NE 13th Street (116A)
Oklahoma City, OK 73104

(405) 270-5183

Email: Michelle-Sherman@ouhsc.edu
Table One. Variables and Measures Used to Assess Family Functioning

<table>
<thead>
<tr>
<th>Variable</th>
<th>Measure Title</th>
<th>Author(s)</th>
<th>Other Uses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge of mental illness</td>
<td>Mental Illness Questionnaire</td>
<td>Falloon et al., 1984</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Family Education Information Test</td>
<td>Bisbee, 1991</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Knowledge Questionnaire</td>
<td>Smith &amp; Birchwood, 1987</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Knowledge about Schizophrenia Interview</td>
<td>Barrowclough et al., 1987</td>
<td></td>
</tr>
<tr>
<td>Level of expressed emotion in family</td>
<td>Expressed Emotion</td>
<td>Berkowitz et al., 1981</td>
<td>Zastowny et al., 1992</td>
</tr>
<tr>
<td>Attitude toward mental illness</td>
<td>Attitude Checklist</td>
<td>Bisbee, 1991</td>
<td></td>
</tr>
<tr>
<td>Attitude toward patient</td>
<td>(no specific measure)</td>
<td>Mannion et al., 1994</td>
<td>Posner et al., 1992</td>
</tr>
<tr>
<td>Level of overall psychological distress of family member</td>
<td>Brief Symptom Inventory (BSI)</td>
<td>Derogatis &amp; Melisaratos, 1983</td>
<td>Pakenham &amp; Dadds, 1987</td>
</tr>
<tr>
<td></td>
<td>Symptom Rating Test (SRT)</td>
<td>Cochrane, 1980</td>
<td>Birchwood et al., 1992</td>
</tr>
<tr>
<td>Level of depression in caregiver</td>
<td>Center for Epidemiological Studies Depression Scale (CES-D)</td>
<td>Radloff, 1977</td>
<td>Rauktis et al., 1995</td>
</tr>
<tr>
<td>Level of anxiety in family member</td>
<td>State and Trait Anxiety Scale</td>
<td>Spielberger et al., 1970</td>
<td>Abramowitz &amp; Coursey, 1989</td>
</tr>
<tr>
<td>Psychosomatic symptoms in family members</td>
<td>Involvement Evaluation Questionnaire (IEQ)</td>
<td>Schene &amp; Van Wijngaarden, 1992</td>
<td></td>
</tr>
<tr>
<td>Variable</td>
<td>Measure Title</td>
<td>Author(s)</td>
<td>Other Uses</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------</td>
<td>--------------------------------</td>
<td>-----------------------------------</td>
</tr>
<tr>
<td>Level of caregiver burnout</td>
<td>Emotional exhaustion subscale of Maslach Burnout Inventory (MBI)</td>
<td>Maslach &amp; Jackson, 1986</td>
<td>Cuijers &amp; Stam, 2000</td>
</tr>
<tr>
<td>Level of objective burden on family member</td>
<td>Involvement Evaluation Questionnaire (IEQ)</td>
<td>Schene &amp; Van Wijngaarden, 1992</td>
<td></td>
</tr>
<tr>
<td>Level of subjective burden on family member</td>
<td>Relative Distress Scale</td>
<td>Greene, 1982</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Social Behavior Assessment Schedule (SBAS)</td>
<td>Platt et al., 1983</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Family Distress Scale</td>
<td>Smith &amp; Birchwood, 1987</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Subjective Burden Scale</td>
<td>Potasnik &amp; Nelson, 1984</td>
<td></td>
</tr>
<tr>
<td>Level of both objective and subjective burden on caregiver</td>
<td>Burden Assessment Scale (BAS)</td>
<td>Reinhard et al., 1994</td>
<td></td>
</tr>
<tr>
<td>(independent of patient’s disruptive behavior and demands of caregiving activities)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Additional financial burden on the family</td>
<td>Involvement Evaluation Questionnaire (IEQ)</td>
<td>Schene &amp; Van Wijngaarden, 1992</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Family Economic Burden Interview</td>
<td>Clark &amp; Drake, 1994</td>
<td></td>
</tr>
<tr>
<td>Family member’s embarrassment</td>
<td>Embarrassment Scale</td>
<td>Freeman &amp; Simmons, 1961</td>
<td>Thompson &amp; Doll, 1982</td>
</tr>
<tr>
<td>Consequences on children and family</td>
<td>Involvement Evaluation Questionnaire (IEQ)</td>
<td>Schene &amp; Van Wijngaarden, 1992</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Experience of Caregiving Inventory</td>
<td>Szmuker et al., 1996</td>
<td></td>
</tr>
<tr>
<td>Variable</td>
<td>Measure Title</td>
<td>Author(s)</td>
<td>Other Uses</td>
</tr>
<tr>
<td>----------------------------------------------</td>
<td>----------------------------------------------------</td>
<td>----------------------------</td>
<td>-----------------------------</td>
</tr>
<tr>
<td>Family coping abilities</td>
<td>Experience of Caregiving Inventory (no specific measure)</td>
<td>Szmukler et al., 1996</td>
<td>Pakenham &amp; Dadds, 1987</td>
</tr>
<tr>
<td>Grief/loss</td>
<td>Experience of Caregiving Inventory</td>
<td>Szmukler et al., 1996</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Texas Inventory of Grief – Mental Illness Version</td>
<td>Miller et al., 1990</td>
<td></td>
</tr>
<tr>
<td>Self-efficacy</td>
<td>Generalized Self-Efficacy Scale (no specific measure)</td>
<td>Tipton &amp; Worthington, 1984</td>
<td>Solomon et al., 1997</td>
</tr>
<tr>
<td>Positive aspects of caregiver’s role</td>
<td>Experience of Caregiving Inventory</td>
<td>Szmukler et al., 1996</td>
<td></td>
</tr>
<tr>
<td>(including “rewarding personal experiences”</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>and “good aspects of relationship with patient”)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table Two. Demographic Characteristics of SAFE Program Participants (n=288) in the First 8 Years (1999-2007) at the Oklahoma City VA Medical Center

<table>
<thead>
<tr>
<th>Range</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant’s Age</td>
<td></td>
</tr>
<tr>
<td>17-25</td>
<td>7.0</td>
</tr>
<tr>
<td>26-39</td>
<td>13.2</td>
</tr>
<tr>
<td>40-49</td>
<td>19.1</td>
</tr>
<tr>
<td>50-59</td>
<td>33.3</td>
</tr>
<tr>
<td>60-69</td>
<td>16.3</td>
</tr>
<tr>
<td>70 +</td>
<td>10.8</td>
</tr>
<tr>
<td>Participant’s Gender</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>79.9</td>
</tr>
<tr>
<td>Male</td>
<td>20.1</td>
</tr>
<tr>
<td>Consumer’s Primary Diagnosis</td>
<td></td>
</tr>
<tr>
<td>PTSD</td>
<td>56.7</td>
</tr>
<tr>
<td>Major Depression</td>
<td>18.1</td>
</tr>
<tr>
<td>Schizophrenia</td>
<td>14.8</td>
</tr>
<tr>
<td>Bipolar Disorder</td>
<td>10.4</td>
</tr>
<tr>
<td>Number of Years Consumer Has Had Diagnosis</td>
<td></td>
</tr>
<tr>
<td>0-1</td>
<td>12.2</td>
</tr>
<tr>
<td>2-10</td>
<td>31.3</td>
</tr>
<tr>
<td>11-20</td>
<td>17.4</td>
</tr>
<tr>
<td>21-30</td>
<td>19.4</td>
</tr>
<tr>
<td>31 +</td>
<td>6.9</td>
</tr>
<tr>
<td>Relationship to Consumer</td>
<td></td>
</tr>
<tr>
<td>Wife</td>
<td>45.8</td>
</tr>
<tr>
<td>Mother</td>
<td>11.8</td>
</tr>
<tr>
<td>Child</td>
<td>9.4</td>
</tr>
<tr>
<td>Friend</td>
<td>7.0</td>
</tr>
<tr>
<td>Husband</td>
<td>4.9</td>
</tr>
<tr>
<td>Sibling</td>
<td>4.2</td>
</tr>
<tr>
<td>Other</td>
<td>17.0</td>
</tr>
<tr>
<td>Amount of Contact with Consumer</td>
<td></td>
</tr>
<tr>
<td>Extensive</td>
<td>56.6</td>
</tr>
<tr>
<td>Moderate</td>
<td>22.6</td>
</tr>
<tr>
<td>Minimal</td>
<td>9.0</td>
</tr>
<tr>
<td>Rare</td>
<td>4.2</td>
</tr>
</tbody>
</table>

Note: Not all items sum to 100% due to participants’ not completing the question.
SAFE Program
Background Information Form

Name: ____________________________________________
Family member's name: ____________________________________________
Family member's diagnosis(es): ____________________________________________
Number of years family member has been dealing with above diagnosis: ___ years

Your relationship to family member (e.g., spouse): ________________________________

Extent of your involvement or contact with family member:

<table>
<thead>
<tr>
<th>Rare (once/week or less)</th>
<th>Minimal (once every few days)</th>
<th>Moderate (daily)</th>
<th>Extensive (24 hours/day)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

How did you learn about the SAFE Program? ________________________________

Please answer the following questions about your family member's behavior:

1. In the past 2 years, how many inpatient psychiatric hospitalizations has he/she had (at this VA or other hospitals)?
   0  1  2  3  4/more

2. In the past 2 years, approximately what percentage of his/her appointments with the mental health providers (psychiatrists, psychologists, etc.) has he/she attended?
   0%  25%  50%  75%  100%

3. In the past 3 months, what percentage of days has your family member taken his/her medications as prescribed?
   0%  25%  50%  75%  100%

Please answer the following questions about your experiences and feelings over the past 30 days:

1. How confident do you feel in dealing with your family member's mental illness?
   1  2  3  4  5
   not at all confident  somewhat confident  very confident

Support And Family Education:
Mental Health Facts for Families
Michelle D. Sherman, Ph.D.
2. How many days in the past month have you had difficulty managing your family member's behavior?

<table>
<thead>
<tr>
<th></th>
<th>0-5</th>
<th>6-10</th>
<th>11-20</th>
<th>21-27</th>
<th>28+</th>
</tr>
</thead>
</table>

3. How distressed or anxious are you about your family member's well-being?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>low level of distress</td>
<td>moderate distress</td>
<td>very high distress</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

4. How much do you understand about your family member's mental illness?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>very little</td>
<td>some</td>
<td>a great deal</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

5. How much do you know about what is available at this VA Medical Center to help your family member when problems arise?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>very little</td>
<td>some</td>
<td>a great deal</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

6. How well are you able to take care of yourself and meet your own personal needs?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>very poorly</td>
<td>somewhat</td>
<td>very well</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

We are committed to studying the helpfulness of this program over time.

Would you be willing to be contacted in the future about your experiences?

Yes    No

If Yes, please print your address and home phone number below:

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

Phone Number: (     )

Thank you!
Publications Regarding the SAFE Program


Citation for Manual:

The SAFE Program: A Family Psychoeducational Curriculum Developed in a Veterans Affairs Medical Center

Michelle D. Sherman
Oklahoma City Veterans Affairs Medical Center and University of Oklahoma Medical Center

One of the unintended positive consequences of deinstitutionalization and managed care restrictions has been an increased awareness of the impact of serious mental illness on the family. The Support and Family Education (SAFE) Program: Mental Health Facts for Families is a 14-session curriculum of monthly workshops for caregivers. In contrast to similar programs, the SAFE Program is facilitated by mental health professionals, is not diagnostic specific, and includes attention to posttraumatic stress disorder. Three years of outcome data reveal that program attendance is related to increased understanding of mental illness and enhanced awareness of Veterans Affairs resources. Workshop attendance is positively correlated with improvements in participants’ self-care. The entire SAFE Program manual is available free of charge on the Internet (http://w3.ouhsc.edu/safeprogram).

What happens when our clients with serious mental illnesses leave our offices or inpatient units? Are they greeted by supportive family members who understand mental illness and can participate in the treatment/discharge plans? Or might our clients’ families be so overwhelmed, confused, and frustrated that they feel like giving up? Or might all social support be gone? Furthermore, how much do mental health professionals involve the family members who come faithfully to appointments or during visiting hours, only to sit in our waiting rooms or be denied access to professionals? How much do we reach out to the families that never participate in their loved one’s treatment? Unfortunately, very little research has been done to answer these questions, despite the large number of families caring for individuals with severe mental illnesses. When psychologists dedicate their time, energy, and expertise to supporting and educating caregivers, significant benefits emerge for both clients and families.

Approximately one in every five Americans experiences a mental illness in a given year (Satcher, 1999), and 40–65% of adults with a serious and persistent mental illness reside with their families (Solomon & Draine, 1995). Historically, including family members in the client’s care has been “fraught with ambivalence at best; neglect or hostility at worst” (Gantt, Goldstein, & Pinsky, 1989), largely because of the damaging hierarchical, adversarial, and family blaming mentalities that pervaded the mental health system. More recently, however, societal changes and advocacy groups’ influences have turned mental health professionals’ attention increasingly toward the family.

For example, deinstitutionalization has resulted in family members having greater responsibility for caring for their loved ones without the necessary knowledge, skills, and support (Cuijpers & Stam, 2000; Solomon, 1996). Many families have been affected by these changes, as the number of clients in public psychiatric hospitals decreased by 82% between 1955 and 1988 (Mechanic & Rochefort, 1992). As a result, family members who were accustomed to periodic hospital visits had to adjust to the client living with the family. As psychopharmacology alone is often insufficient to maintain a high quality of life for the client, family members can be forced into the role of “de facto therapists” (Thompson & Doll, 1982, p. 379).

In addition, managed care has led to greater restrictions on the access and amount of mental health care; both clients and family members have to work harder to receive services that are not deemed a medical necessity (Lefley, 1994; Marsh, 1998). The brevity and infrequency of outpatient appointments have resulted in fewer opportunities for both clients and families to get support and education. Similarly, hospital lengths of stay have dramatically shortened.

Advocacy organizations, such as the National Alliance for the Mentally Ill (NAMI), have grown in strength and influence, striving to combat stigma and the family blaming mentality (Hatfield, 1994). State chapters of NAMI support families and encourage involvement in the client’s treatment, educate communities about mental illness, lobby for the rights of the mentally ill, and advocate for research funding on the prevention and treatment of mental illness. Fortunately, many mental health professionals are making a similar paradigm shift in their view of families, moving away from a focus on pathology (a disease-based medical model that focuses on diagnoses and dysfunction) to a competence paradigm.

Michelle D. Sherman received her PhD in clinical psychology from the University of Missouri—Columbia in 1997. She is the director of the Family Mental Health Program at the Oklahoma City Veterans Affairs Medical Center. She is a clinical assistant professor in the Department of Psychiatry and Behavioral Sciences at the University of Oklahoma Medical Center and an adjunct assistant professor of psychology at Oklahoma State University. She is an affiliate research investigator in the South Central Mental Illness Research, Education and Clinical Center (MIRECC). Her areas of interest include family psychoeducation regarding mental illness, couples/family psychotherapy, and bereavement.

Special thanks to the South Central MIRECC for their support in creating the SAFE Program manual, as well as to Andrea Vincent and Kristen Sorocco for their helpful feedback on this article.

Correspondence concerning this article should be addressed to Michelle D. Sherman, Family Mental Health Program, Oklahoma City Veterans Affairs Medical Center, 921 NE 13th Street (116A), Oklahoma City, Oklahoma 73104-5028. E-mail: michelle.sherman@med.va.gov.
(a health-based approach addressing family strengths, resources, and empowerment; Marsh, 1992).

As mental health professionals turned their attention to families in the late 1980s and early 1990s, the preliminary task was to understand the caregiving experience. Addressing caregivers’ needs is vital because individuals with mental illness so commonly “reject medical diagnoses, refuse to participate in efforts to become well, are angry and hostile toward caregivers, and are unable to express gratitude for the care they receive” (Karp & Watts-Roy, 1999, p. 487). Family members report that they need education about mental illness, coping skills, emotional support (especially during crises), and more open communication with professionals (Biegel, Song, & Milligan, 1995; Gaskill & Cooney, 1992).

Pioneers in the study of families were also guided by early work on expressed emotion (EE). The level of EE in a family is highly predictive of symptomatic relapse in recently discharged clients with schizophrenia who are in contact with their families (e.g., Vaughn, Snyder, Jones, Freeman, & Falloon, 1984). Family participation in well-designed psychoeducational programs can reduce client relapse rates and improve adherence to treatment (Dixon & Lehman, 1995; Dixon, Adams, & Lucksted, 2000). A recent meta-analysis (Falloon, Roncone, Held, Coverdale, & Laidlaw, 2002) of 23 controlled studies examined the benefits of family psychoeducation regarding schizophrenia when added to standard pharmacotherapy and case management; the benefits included reduced risk of relapse, remission of residual psychotic symptoms, enhanced social and family functioning, and financial savings (because of decreased need for intensive services).

Family psychoeducational programs also yield positive outcomes for caregivers. For example, NAMI’s Family-to-Family Program (previously titled the Journey of Hope Education Program) has demonstrated improved caregiver morale and knowledge of mental illness (Picket-Schenk, Cook, & Laris, 2000), enhanced feelings of empowerment in the community and family, and lessened worry and displeasure about their loved ones (Dixon et al., 2001). When caregivers cope effectively with the client’s behavior, they report fewer psychosomatic symptoms and a lower level of burnout (Cuipers & Stam, 2000).

Sparked by these societal changes, the influence of advocacy groups, and the research demonstrating the efficacy of family psychoeducational programs, several standards have been defined. Numerous Veterans Affairs (VA) directives mandate family education, and customer service standards urge providers to “improve patient and family satisfaction.” Joint Commission on Accreditation of Healthcare Organizations (JCAHO) standards encourage patient and family education. The Schizophrenia Patient Outcomes Research Team (PORT) treatment recommendations outline a family intervention lasting at least 9 months addressing education, support, problem solving, and crisis management (Lehman, Steinwachs, & Survey Co.—Investigators of the PORT Project, 1998). Similarly, the American Psychiatric Association’s best practice guidelines (American Psychiatric Association, 1998) and the expert consensus guidelines for schizophrenia (Frances, Docherty, & Kahn, 1996) encourage family education and support programs.

However, even with these standards and convincing data, very few families receive services (Burland, 1998; Dixon et al., 1999; Falloon et al., 2002). For example, less than 10% of families of outpatients with schizophrenia receive support or education, in spite of the fact that most of these families have regular contact with the clients (Lehman et al., 1998). Even though most mental health providers believe educating families about mental illness is very important (Constandeda & Sommer, 1989), relatively few commit the requisite time and energy to provide these services. Although NAMI has fortunately secured contacts with many state departments of mental health to provide their Family-to-Family Program (Burland, 1998), the vast majority of families are not receiving any services at all.

Overview of Family Education Programs

Family education programs vary in their format, target population, duration, enrollment (closed vs. ongoing entry), goals, and mode of intervention. For example, psychoeducation can be provided in a multifamily group structure (McFarlane, Hornby, Dixon, & McNary, 2002), in a family therapy setting, and/or in a family consultation model (Marsh & Johnson, 1997). Programs may have an educational focus, a skills-building approach, a strictly supportive focus, or some combination of the three. Many programs focus on a specific mental illness, typically schizophrenia (e.g., Amenson, 1998; Atkinson & Coia, 1995; McFarlane et al., 2002) or bipolar disorder (e.g., Miklowitz & Goldstein, 1997), whereas others focus on the major mental disorders (e.g., Bisbee, 1995; Burland, 1993). None of the programs examined in this review had specific information on coping with posttraumatic stress disorder (PTSD), which is a notable gap in the family education literature.

Most programs exclude the clients from the family meetings, as client involvement has been found to inhibit the educational process (Reilly, Rohbaugh, & Lachner, 1988). The majority of programs target all adult family members (parents, siblings, adult children, and so forth), whereas some (e.g., program for spouses in Mannion, Mueser, & Solomon, 1994) focus specifically on the needs of a particular relative (see Marsh, 1998, for a review of specific needs of various family members). Although mental health professionals facilitate some courses, many programs train family members to teach the classes (e.g., Burland, 1993). Interventions range from a single-session educational workshop to intensive programs of 15 classes or more (e.g., Cuipers, 1999). Excellent reviews of several model programs have been recently published (e.g., Leffley & Johnson, 2002; Marsh, 1998, 2001; Mueser & Glynn, 1999).

The SAFE Program

The Support and Family Education (SAFE) Program: Mental Health Facts for Families is a 14-session curriculum that was created in a VA setting. Feedback from a preliminary needs assessment (created by and available from Michelle D. Sherman) helped guide program development. Ninety-minute workshops are provided on a monthly basis, and caregivers can attend whenever they wish. The program has several distinct features. First, the SAFE Program is not specific to any one psychiatric diagnosis and therefore appeals to a wide range of caregivers. Given the similar needs among family members, most of the sessions deal with mental illness in general. Family members with quite different home situations apply the didactic information to their unique
situations and learn from each other. Disorder-specific resources are also available.

Second, the SAFE Program includes one session specifically focusing on PTSD, a common problem for many of the veterans. Other session outlines (e.g., “What can I do when my loved one is angry or violent?”) also include examples that are relevant to living with PTSD in the family. Other psychoeducational programs may teach generally about anxiety disorders, but the challenges of living with PTSD in the family have been ignored.

Third, the program is provided within a familiar VA setting. Family members often trust VA mental health professionals as having specific expertise in working with PTSD, thereby making a program on site by VA staff especially appealing.

Fourth, in contrast to the popular Family-to-Family Program in which trained volunteer family members lead workshops, a psychologist facilitates the SAFE Program. Although peer support and education can be very valuable, psychologists have a broader knowledge base, skills in group facilitation, and, frequently, institutional support to provide beneficial programming. Mental health professionals’ commitment to families attests to the overt shift away from our historic neglect of families, who were viewed as pathogenic, to now viewing caregivers as potentially competent, supportive collaborators (Marsh, 1992). Fifth, a psychiatrist attends part of every SAFE workshop to answer questions about medications. Finally, the SAFE Program is provided on an ongoing basis in contrast to the time-limited nature of many family programs. The availability of peer and professional support over time can be invaluable to caregivers coping with the oftentimes chronic and cyclical nature of mental illness.

Goals

The SAFE Program has six major goals: (a) to teach caregivers about the symptoms and course of mental illness; (b) to afford family members the opportunity to ask questions about psychiatric disorders and treatment options; (c) to reduce the stigma of mental illness by providing a forum in which to discuss concerns and obtain support from peers; (d) to publicize the availability of mental health services at the medical center; (e) to help family members understand the importance of early intervention for their loved one, as well as open, timely communication with providers; and (f) to link family members with opportunities for support both at the VA and in the community (including the local NAMI affiliate).

Publicity

Publicity is an ongoing and time-intensive effort, as new clients and providers continually enter the VA system. Monthly flyers are posted throughout the medical center. Information is disseminated to three groups: eligible family members, clients enrolled in mental health treatment programs, and medical center and community providers.

Invitation letters were sent to all family members who had completed the needs assessment. A pamphlet is given to caregivers of clients on admission and/or discharge from the inpatient psychiatric unit. To publicize the program to clients, a brief blurb announcing the next SAFE workshop is placed on the bottom of all appointment letters from the outpatient mental health clinic (which averages 18,000 appointments per year). The availability of the program is announced at all mental health psychoeducational classes, and presentations are made regularly in various mental health programs. Provider publicity is achieved by means of annual distribution of schedules and pamphlets to staff throughout the medical center. Articles have been published in various newsletters, including the state psychological and psychiatric associations newsletters, veteran newsletters, VA professional newsletters, and VA Web sites.

Workshop Format

Each workshop has three sections: group discussion and support, a didactic presentation, and a question-and-answer period with a psychiatrist. Caregivers are given a participant notebook at their first workshop, which contains helpful handouts, newsletters, and resource lists (including diagnostic-specific books, Web sites, and community resources, such as NAMI). Family members may also borrow books or videos from the resource library.

At the beginning of every workshop, caregivers complete a participant background information form (created by and available from Michelle D. Sherman) that assesses their experiences in the past 30 days regarding the following: confidence in dealing with client’s mental illness (5-point Likert scale ranging from not at all confident to very confident); number of days caregiver had difficulty coping with client’s behavior (choices of 0–5, 6–10, 11–20, 21–27, and 28+ days); level of distress about client’s well being (5-point Likert scale ranging from low level of distress to very high distress); understanding of mental illness (5-point Likert scale ranging from very little to a great deal); knowledge of VA treatment resources (5-point Likert scale ranging from very little to a great deal); and ability to take good care of themselves (5-point Likert scale ranging from very poorly to very well). In addition, participants indicated the percentage of mental health appointments that the client attended in the past 2 years (choices of 0, 25, 50, 75 or 100%).

The workshop begins with a review of the program goals and confidentiality. Given that caregiving is often a thankless, challenging, and lonely endeavor, each participant’s dedication to his or her loved one is affirmed. As the participants’ presence at the workshop signifies a desire to know more about how to help their loved ones, the caregivers are genuinely thanked for their commitment. Next, family members have an opportunity to introduce themselves, including their reason for attending the workshop and any current challenges or successes.

A 30–45-min didactic presentation and discussion follows the check-in period. Each workshop has a specific topic (e.g., “What causes mental illness”). Detailed session outlines include the following: ready-to-present text reviewing basic information on the session’s topic, discussion questions, group activities, suggested videotape clips, and session handouts. For example, the session on the causes of mental illness includes a group discussion of the common myths surrounding mental illness, a presentation of the biopsychosocial model and the diathesis-stress model, and a viewing of a brief videotape on the biological contributions to mental illness. See Table 1 for a listing of the 14 sessions.

A psychiatrist attends the last 15 min of each workshop, giving participants the opportunity to ask questions about medication issues. The psychiatrist does not give any specific advice or
Table 1

SAFE Program Sessions

<table>
<thead>
<tr>
<th>Session title</th>
</tr>
</thead>
<tbody>
<tr>
<td>What causes mental illness?</td>
</tr>
<tr>
<td>What can I do when my family member is depressed?</td>
</tr>
<tr>
<td>What can I do when my family member is angry or violent?</td>
</tr>
<tr>
<td>Communication tips with family members</td>
</tr>
<tr>
<td>Limit setting and boundaries with family members</td>
</tr>
<tr>
<td>How can I take care of myself as a caregiver?</td>
</tr>
<tr>
<td>Rights and responsibilities of patients, family members, and professionals</td>
</tr>
<tr>
<td>What do we tell our children and other people about mental illness?</td>
</tr>
<tr>
<td>Stress-busting tips for family members</td>
</tr>
<tr>
<td>What to do when your help is turned away</td>
</tr>
<tr>
<td>Do’s and don’ts in helping your family member</td>
</tr>
<tr>
<td>Tips to help make the holiday season pleasant</td>
</tr>
<tr>
<td>PTSD and its impact on the family</td>
</tr>
<tr>
<td>Schizophrenia and its impact on the family</td>
</tr>
</tbody>
</table>

Note. SAFE = Support and Family Education; PTSD = posttraumatic stress disorder.

recommendations on medications but answers questions about purposes of specific drugs, common side effects, possible drug interactions, and so forth.

A representative from the local NAMI frequently attends the workshops. She describes the mission and activities of NAMI, addresses advocacy issues, and publicizes community events. The workshops close with the completion of evaluation forms and the distribution of self-care items (e.g., candles, bookmarks, journals) to signify our appreciation of the participants’ commitment to veterans.

Participation

In the first 3 years, 115 individuals attended the SAFE Program. The number of participants per workshop ranged from 4 to 25 ($M = 9.0, SD = 4.3$), with attendance steadily increasing over time. The sessions with the highest attendance included “PTSD and its impact on the family” ($M = 17.5, SD = 3.5$). “How can I take care of myself as caregiver?” ($M = 11.0, SD = 6.1$), and “What can I do when my family member is angry or violent?” ($M = 10.0, SD = 4.0$).

Regarding participant demographics, 77.4% ($n = 89$) were women and 22.6% ($n = 26$) were men. Consistent with the current veteran population, 56.5% ($n = 65$) of the participants were in their 40s and 50s, 27.8% ($n = 32$) were over 60, and 15.6% ($n = 18$) were under 40. Almost all of the participants (91.3%, $n = 105$) were European American. With respect to each participant’s relationship to the veteran, 40.9% ($n = 47$) were wives, followed by 12.2% ($n = 14$) mothers, 11.3% ($n = 13$) children, and 35.6% ($n = 41$) “other” (e.g., husband, sibling, friend). Considerable variability existed in the clients’ diagnoses, including 33.9% ($n = 39$) PTSD, 22.6% ($n = 26$) major depressive disorder, 18.3% ($n = 21$) bipolar disorder, 15.7% ($n = 18$) schizophrenia, and 9.6% ($n = 11$) other. Finally, 47.0% ($n = 54$) of caregivers reported having “extensive/all day” contact with the client, followed by 20.0% ($n = 23$) having “moderate/daily” contact, 10.4% ($n = 12$) having “minimal/once every few days” contact, and 6.1% ($n = 7$) having “rare/once per week or less” contact (19 participants did not answer this item).

Response to the SAFE Program

Data regarding the program are outlined in four sections: description of participants on initial presentation to the SAFE Program, rates and trends in program retention, relationships between attending workshops and other variables, and other mental health professionals’ responses to the program. The participants who were also VA employees did not complete the background information sheets monthly; therefore, most of the following data are based solely on the nonemployee caregivers ($n = 90$).

Description of Participants at Their Initial Presentation

Several interesting group differences emerged in studying the participants on entry into the program. First, in examining relationship to the client, wives reported more understanding of mental illness ($M = 3.4, SD = 1.2$) than non-wives ($M = 2.8, SD = 1.3$), $t(67) = -1.90, p = .03$. Wives also reported greater awareness of VA resources ($M = 2.5, SD = 1.3$) than non-wives ($M = 1.9, SD = 1.3$), $t(67) = -1.74, p = .04$. Although this finding is reasonable based on wives’ greater contact with their spouses, more extensive outreach to other family members (especially siblings and children) will be important as the wives age and are less able to manage the burden of caregiving alone.

Next, comparisons across diagnostic groups revealed interesting differences. Caregivers of veterans with PTSD reported more confidence in caring for the veteran ($M = 3.2, SD = 1.1$) than caregivers of veterans with other mental illnesses ($M = 2.5, SD = 1.3$), $t(70) = -2.19, p = .03$. Similarly, caregivers of veterans with PTSD reported greater awareness of VA resources ($M = 2.6, SD = 1.3$) than other caregivers ($M = 1.9, SD = 1.3$), $t(64) = -2.05, p = .04$. More specifically, wives of veterans with PTSD reported more awareness of VA resources ($M = 2.8, SD = 1.3$) than wives of veterans with other psychiatric disorders ($M = 1.9, SD = 1.2$), $t(29) = 2.08, p = .04$. The VA system has demonstrated its commitment to PTSD by funding research, creating specific treatment programs, and allocating personnel specifically to work with this population. As part of this effort, many medical centers have specific support groups for wives of veterans with PTSD; comparable groups do not exist for other diagnostic categories.

In addition, according to caregiver report only, veterans with PTSD keep a greater percentage of their appointments with mental health providers ($M = 4.5, SD = 0.9$) than veterans with other psychiatric disorders ($M = 3.6, SD = 1.6$), $t(63) = -2.83, p < .01$. Although not formally assessed in this study, it is possible that the availability of specific treatment programs for PTSD enhances treatment adherence. Perhaps the emphasis on this disorder in the VA system has slightly decreased the stigma surrounding accessing care for PTSD, thereby increasing appointment keeping behavior.

Finally, caregivers of veterans with affective disorders (depression and bipolar disorder) reported less understanding of mental illness ($M = 2.7, SD = 1.2$) than did caregivers of individuals with other mental illnesses ($M = 3.3, SD = 1.5$), $t(54) = -2.31, p = .02$. Similarly, caregivers of veterans with affective disorders re-
ported lower awareness of VA resources ($M = 1.8$, $SD = 1.2$) than other caregivers ($M = 2.5$, $SD = 1.9$, $t(54) = -2.20$, $p = .03$). Although many family education/support programs exist for schizophrenia, relatively few target affective disorders (Falloon et al., 2002). Possibly because the affective disorder symptoms can be less provocative or unusual than other disorders, clinicians have not dedicated as much time and energy to family education with these groups. However, this neglect has resulted in these families being less educated about mental illness and less aware of treatment resources. These families often struggle in coping with their loved ones’ major depression episodes, mood swings, suicidal behavior, and so forth; these caregivers could benefit greatly from professional assistance.

**Participant Retention**

Of the 115 individuals (VA employees and nonemployee caregivers) who attended the SAFE Program over the first 3 years, 65.2% ($n = 75$) attended more than one workshop, whereas 34.8% ($n = 40$) attended only one workshop. Of individuals who attended more than one workshop, the average number of workshops attended to date was 6.0 ± 4.5, and the median was four.

With respect to nonemployee caregivers only, over half (51.6%, $n = 16$) of regular attendees had a veteran with PTSD as compared with 37.2% ($n = 16$) of single-workshop attendees. In addition, 77.4% ($n = 24$) of regular attendees lived with the client versus only 53.5% ($n = 23$) of single-workshop attendees.

Some participants lived several hours from the medical center, so transportation and weather conditions may have been barriers to regular attendance. The workshops are offered in midafternoon, so work conflicts prevented some caregivers from attending regularly. In addition, some family members anecdotally reported that their loved ones discouraged them from attending the program because of paranoia or other fears. Even though the program meets once per month and the participants differ each workshop, group cohesion developed quickly among the family members. Participants freely provided support to one another in the workshops, and some exchanged telephone numbers and met socially outside the group. Given the sense of isolation that many caregivers feel, they likely bond quickly out of shared experiences and high levels of need for identification and support.

**Relationships Between Attending SAFE Workshops and Other Variables**

Pearson correlations were examined between the number of SAFE workshops attended and the other six variables assessed at each workshop (excluding the percentage of appointments kept in past 2 years). A significant correlation emerged between the number of workshops attended and the caregiver’s understanding of mental illness ($r = .34$, $p < .01$, $N = 74$). In addition, the relationship between the number of workshops attended and awareness of VA resources ($r = .51$, $p < .0001$, $N = 72$) was strong and positive. Thus, attending this program regularly was associated with greater knowledge of mental illness and of treatment resources.

Finally, to examine the changes in caregivers’ experience over time, change (difference) scores between their data at first workshop and their data at last workshop were reviewed for each variable (only for participants who attended more than one workshop). Pearson correlations between the number of workshops attended and the other six variables were examined, resulting in one significant finding. A strong positive relationship was found between the number of workshops attended and improvements in ability to take care of themselves ($r = .42$, $p = .02$, $N = 71$). As family members came to more workshops, they reported feeling better able to take good care of themselves. Although not empirically examined in this project, one could hypothesize that participants’ improved self-care may enhance their support of their loved ones and overall family functioning.

**Responses From Other Professionals**

The SAFE Program manual was disseminated to every VA network across the country, and many hospitals and clinics are adapting it to meet their specific needs. Locally, providers have responded very positively to the program, and the referral base has expanded to include many units throughout the hospital. Because of the high level of needs of these families, several providers have expressed the sentiment of “we should have had this program a long time ago.” Many providers have indicated that the family members who attend the SAFE Program are more involved in the client’s care, evidenced by attending appointments with the client and calling the provider when problems arise.

Furthermore, the University of Oklahoma Information Design Technology Group created a Web site containing the entire SAFE Program manual (http://w3.ouhsc.edu/safeprogram). The site includes detailed outlines of all 14 sessions, specific information about publicity, literature review, and assessment instruments. The Web site has been available for 20 months and has received over 8,000 hits from 40 American states and 30 countries.

**Satisfaction Data**

Participants completed an anonymous satisfaction questionnaire at the end of every workshop. Four 5-point Likert scale items assessed their perceptions, with stems ranging from 1 (poor) to 5 (excellent). On the basis of 36 months of data (March 1999 through February 2002), the averages were ($n = 314$) as follows: overall quality of presentation, $M = 4.6$, $SD = 0.7$; style of presenter, $M = 4.7$, $SD = 0.7$; relevance of topic, $M = 4.5$, $SD = 0.8$; amount of new information learned, $M = 4.3$, $SD = 0.9$; and overall mean (out of possible 20.0), $M = 18.0$ $SD = 2.6$.

In response to a question about how the workshop had been helpful, the percentages of participants who indicated that specific activities were important are presented in Table 2 (collapsed across all of the workshops, $n = 314$). Receiving handouts, talking to peers, and asking questions of doctors were rated as especially helpful. Anecdotally, many caregivers reported immense relief at having a program dedicated to their needs (one caregiver indicated “I’ve been looking for a program for myself for 5 years in three different states, and this is the first one I’ve found!”).

**Implications for Practitioners in Working With Individuals With Severe Mental Illness**

Amidst deinstitutionalization, managed care restrictions, the rise of advocacy groups, and shifts in conceptualization and provision
of services, mental health care has changed dramatically in the past 50 years. Changes in psychological and psychiatric treatments will undoubtedly continue in the next century with our aging population, and the role of the family will be essential to address in providing comprehensive mental health care. Both hospital-based and independent practitioners would benefit from implementing the following suggestions.

1. Ask regularly about your clients’ support networks. Suggest to your clients that their families become involved in their treatment, and invite families into sessions. Instead of presuming families are “part of the problem,” remember that caregivers can provide invaluable assessment data, emotional support, and assistance in the development and execution of treatment plans. Individual treatment gains are much more likely to be maintained when the client’s broader system is involved. Strive to focus on the family’s present problems rather than the etiology (which can evoke a great deal of guilt).

2. Let go of the strict “psychotherapist” hat and place yourself in the role of educator or consultant. These families are desperate for basic information on the causes, symptoms, treatments, and prognoses of mental illnesses. Provide this information slowly, repeatedly, in layperson’s terms, and in several modalities (e.g., discussion, videotapes, pamphlets, books). Consider a variety of family interventions, such as family consultation, family education, and family therapy (see Marsh & Johnson, 1997).

3. Don’t use confidentiality as an excuse to avoid families. Encourage your clients early in their treatment to sign release-of-information forms (for a sample release form specifically for families, see Marsh, 2001). If the client will not sign the release, remember you can still provide two important services to the family: listening to their concerns (without acknowledging your knowledge of the client) and providing general education about mental illness. Remember that your repeatedly ignoring the family may decrease the likelihood of them participating in treatment later when the client is in crisis. Excellent reviews exist regarding the balance of respecting client confidentiality while still supporting families (Marsh, 2001; Zipple, Langle, Spaniol, & Fisher, 1990).

4. Forget about the outdated 8:00 a.m. to 5:00 p.m. availability with these families, and educate caregivers about how to obtain help in a crisis. Ensure adequate 24-hr-per-day coverage for emergencies.

5. Remember that your clients’ families are usually struggling themselves and often feel lonely and guilty. Caregivers need support, as they often feel considerable stigma and a sense of loss. To enhance your understanding of the family’s perspective, consider reading personal accounts of their experiences (e.g., *Tell Me I’m Here* by A. Deveson [1992]; *His Bright Light: The Story of Nick Traina* by D. Steele [1998]; *My Mother’s Keeper: A Daughter’s Memoir of Growing Up in the Shadows of Schizophrenia* by T. Holley and J. Holley [1997]).

6. Be sensitive to cultural and ethnic issues in the caregiving experience and their resulting implications for supporting and educating families (for a review, see Lefley, 1996, 1998).

7. Learn about community resources for families and encourage caregivers to get involved. Share with families the above-cited research on how their participation can help not only themselves, but also the client. Consider inviting a representative from NAMI to speak at a staff meeting or volunteering some of your time with your local affiliate. If your community lacks a family educational program, consider starting one yourself. For the SAFE Program, contact Michelle D. Sherman or check the Web site for the complete manual. For the Family-to-Family Program, contact NAMI (www.nami.org).

8. To persuade management and/or funding sources to support the creation of a family psychoeducation program, familiarize yourself with the recent best practice guidelines and the striking treatment outcome data that outline the benefits for both clients and families. For example, caregivers who regularly attend programs know more about mental illness and available treatment resources. Armed with this important information and empowered by the group support, family members can assist their loved ones in coping with the oftentimes rocky, cyclical, and chronic course of severe mental illness. Furthermore, caregivers’ ability to take proper care of themselves improves when they attend workshops regularly. Caregivers who are able to meet their own needs can likely provide better care for their loved ones.

9. Given the prevalence of PTSD and its potentially significant impact on the family, other family psychoeducational programs (both in the VA and private sector) would benefit from helping caregivers cope with this often-neglected disorder. These families are often desperate for practical information on how to deal with the client’s confusing and frequently frightening behaviors.

10. Seek out professional educational opportunities for yourself to increase your effectiveness in working with families. For example, interesting workshops sponsored by the Task Force on Serious Mental Illness and Serious Emotional Disturbance are presented at annual American Psychological Association conventions. Highly readable, practical, and concise resources are also available for practitioners (e.g., Lefley, 1996; Marsh, 1998, 2001; Miklowitz & Goldstein, 1997; Mueser & Glynn, 1999).

References


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Table 2

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<thead>
<tr>
<th>Questionnaire item</th>
<th>n</th>
<th>%</th>
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<tbody>
<tr>
<td>Received handouts and a list of resources that apply to my situation</td>
<td>229</td>
<td>82.4</td>
</tr>
<tr>
<td>Had opportunity to talk to other families who face similar issues</td>
<td>189</td>
<td>68.0</td>
</tr>
<tr>
<td>Had opportunity to ask doctors questions about mental illness</td>
<td>184</td>
<td>66.2</td>
</tr>
<tr>
<td>Felt that my role as caregiver is recognized and valued by the VAMC</td>
<td>179</td>
<td>64.4</td>
</tr>
<tr>
<td>Learned new ideas about how to help my family member</td>
<td>163</td>
<td>58.6</td>
</tr>
<tr>
<td>Learned more about the treatments of mental illness</td>
<td>148</td>
<td>53.2</td>
</tr>
<tr>
<td>Increased my awareness of various resources at the VAMC</td>
<td>136</td>
<td>48.9</td>
</tr>
<tr>
<td>Learned more about the definitions of mental illness</td>
<td>136</td>
<td>48.9</td>
</tr>
<tr>
<td>Learned more about the causes of mental illness</td>
<td>117</td>
<td>42.1</td>
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</table>

Note. VAMC = Veterans Affairs Medical Center.


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Revision received August 14, 2002
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I am invested in expanding our knowledge and use of family education regarding mental illness. I sincerely welcome your reactions, comments, experiences, questions and ideas.

I can be reached at:

Michelle D. Sherman, Ph.D.
Director, Family Mental Health Program
Oklahoma City VA Medical Center
921 NE 13th Street (116A)
Oklahoma City, OK 73104

(405) 270-5183
Or you may email me at: Michelle-Sherman@ouhsc.edu
SAFE Program Implementation Toolkit
Michelle Sherman, Ph.D., January 2009

3-4 months before start date

Planning Stages

ENLIST SUPERVISORY / MANAGEMENT SUPPORT:

- Discuss the plan to implement the SAFE Program with your service chief / line director and obtain his/her approval and support.

- Ensure that sufficient time is allotted to program development and actual class provision (possibly including relief from other existing duties).

PERSONNEL:

- Define personnel who will facilitate classes (Have one or two core staff that are present every session, but can have occasional guest speakers to present didactic material if desired to decrease burden on staff).
  - Facilitators need skills in group facilitation; knowledge of serious mental illness / PTSD; and compassion for and insight into the experience of families.
  - The facilitator could be a psychologist, psychiatrist, social worker, psychiatric nurse, or therapist.

- Facilitators should read:

  For background information on the SAFE Program:


  For suggestions about creating family programming in a new setting:
Solicit volunteers from psychiatry or pharmacy to come for 10-15 minutes for Q&A time regarding medication issues.

Create schedule for the year indicating who will attend to address medication issues in each class.

LOGISTICS:

Select location for classes.
- Room should be comfortable and easily accessible for families.
- The classroom should allow for chairs to be put in a circle to enhance group discussion.
- Room needs a dry erase board.
- It’s preferable to have audiovisual set-up to be able to show videotapes or DVDs.

Select time of day / day of week to accommodate local needs.

Reserve room for classes.

DOCUMENTATION / WORKLOAD (also see pages 23-24 of manual):

Meet with MAS (Medical Administrative Support) staff to discuss how to create a collateral record. If MAS needs additional guidance, refer them to page 22 (Section 6: Documentation) of this document from the Office of Care Coordination. [http://vaww.carecoordination.va.gov/topics/caregiver/docs/CGFAQ.pdf](http://vaww.carecoordination.va.gov/topics/caregiver/docs/CGFAQ.pdf)

Create a non-billable clinic (but one that creates workload) – e.g., SAFE clinic.

Create progress note template – see website or pg 24 of manual for sample.

Familiarize staff with proper codes.
- CPT = 90887: “Interpretation or explanation of results of psychiatric, other medical examinations and procedures, or other accumulated data to family or other responsible persons, or advising them how to assist patient.”
- DX = v65.0 (“healthy family member accompanying sick”)
- Stop Code = 550
PUBLICITY:

Create publicity materials

- Create annual schedule poster – for sample, see pg 29 of manual or: http://w3.ouhsc.edu/safeprogram/annual_schedule.html
- Create flyers (to be hung throughout mental health units) announcing upcoming class – for sample, see pg 30 of manual or http://w3.ouhsc.edu/safeprogram/flyer.html
- Create tri-fold pamphlets (brochure) describing program – for sample, see pg 28 of manual or http://w3.ouhsc.edu/safeprogram/brochure.html
- Create reminder letter template – for sample, see pg 31 of manual or http://w3.ouhsc.edu/Safeprogram/ReminderLetter.pdf

One month prior to start of program:

Inform referral sources: INTERNAL (your own medical center / CBOC’s)

- Attend each unit’s staff meetings and provide brief presentation and provide publicity materials.
- Present at your local Consumer Council meeting and provide publicity materials.
- Present at each CBOC in your region and provide publicity materials.
- Present at your Education Council.
- Create packets for all relevant VA staff (for listing of such staff, see pg 27 or manual or http://w3.ouhsc.edu/safeprogram/Publicity_Efforts.html on website). Packets may include:
  1. Personalized cover letter explaining program and requesting referrals
  2. Annual schedule (ask them to post in their office)
  3. Stack of flyers
Inform referral sources: EXTERNAL (beyond your medical center)

- Have face-to-face meeting with local NAMI affiliate and provide publicity materials. Emphasize how the SAFE Program includes information on PTSD (whereas NAMI’s Family to Family AND Journey of Hope courses do not).

- Present at your local Vet Centers and provide publicity materials.

- Make personal contact and mail publicity materials to all community mental health centers (CMHCs) in your area.
Preparation for Classes

- Create Participant Notebooks, namely 3-ring binders consisting of:
  - “Welcome to the SAFE Program” handout – for sample, see pg 13 of manual or [http://w3.ouhsc.edu/Safeprogram/HandOut-A.pdf](http://w3.ouhsc.edu/Safeprogram/HandOut-A.pdf)
  - SAFE tri-fold pamphlet
  - SAFE Resource list – see pg 14 of manual or [http://w3.ouhsc.edu/Safeprogram/HandOut-B.pdf](http://w3.ouhsc.edu/Safeprogram/HandOut-B.pdf)
  - NAMI pamphlet (from local NAMI affiliate)
  - Several sheets of blank paper for note taking

- Create sign-in sheets including:
  Family member’s:
  - Full name
  - Date of birth
  - Full social security number
  - Mailing address
  Veteran’s:
  - Full name
  - Last four digits his/her social security number

- Make copies of:
  - Background information form (to be completed at every session) – pg 221 of manual or [http://w3.ouhsc.edu/Safeprogram/HandOut-2.pdf](http://w3.ouhsc.edu/Safeprogram/HandOut-2.pdf)
  - Satisfaction form – for sample, see pg 213 of manual or: [http://w3.ouhsc.edu/Safeprogram/HandOut-HH.pdf](http://w3.ouhsc.edu/Safeprogram/HandOut-HH.pdf)
Preparation for Each Class

☐ Gather materials: For a list of materials needed for each session, see pg 8 of manual or http://w3.ouhsc.edu/safeprogram/MaterialsNeeded.html

☐ Review the session outline, making notes of anecdotes and examples you may wish to use.

☐ Make photocopies of the handouts for the class. Ensure that they are 3-hole punched so participants can keep them in their Participant Notebook.

After Each Class

☐ Ask MAS clerk to create “collateral chart” for each participant.

☐ Load the appointment for each participant.

☐ Write the progress note.

☐ Complete the encounter.

☐ Enter the anonymous satisfaction data into excel spreadsheet to track over time. For sample, see next page.
SAFE Evaluation Form

<table>
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<th>Quality</th>
<th>Presenter</th>
<th>Style</th>
<th>Relevance</th>
<th>New Info</th>
<th>Sum</th>
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<th>Txs</th>
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<th>VA Res</th>
<th>Commt Resource</th>
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Mean: 4.71 4.79 4.57 4.50 18.65
n: 14 14 14 14 14
Stdev: 0.47 0.43 0.65 0.52 1.39

Percent Endorsed: 100% 100% 79% 93% 71% 79% 100% 64% 93% 100%

1 = yes
0 = no

3/27/2009
SAFE Program Implementation Toolkit
Appendix on Provision in a Rural Area or VA Community Based Outpatient Clinic (CBOC)
Michelle D. Sherman, Ph.D., Ellen Fischer, Ph.D., Ursula Bowling, Psy.D.
Peggy Hudson, Ph.D., Russell Smith, Ph.D.
September 2010

The SAFE Program was originally developed in a VA medical center setting. As the VA system strives to provide services to our rural veterans and improve access to care, questions have arisen about the possibility of offering SAFE in rural areas and possibly through Community Based Outpatient Clinics (CBOCs). As each CBOC has its own unique culture, patient population, and providers (including varying levels of interest and experience in working with families), a blanket recommendation that would suit all locations is not feasible. This appendix is an attempt to provide information on frequently asked questions, identify issues for consideration during the program development phase, and summarize experience on the advantages and disadvantages of various approaches.

The following information was ascertained via

- Interviews with staff at three CBOCs in VISN 16, ranging from a small CBOC to a large one.
- Focus groups with rural veterans (some who use CBOCS for their care, others who choose to drive a long distance to a medical center).
- Focus groups with rural family members (some from CBOCs and others from a large medical center).

Do rural families WANT education about mental illness/PTSD?

YES. Every person we interviewed (n=54) expressed a strong desire for family education, and many expressed high levels of willingness to do whatever it took to make it happen and to participate. Further, very few rural families report having received any education about their veteran’s mental illness/PTSD.

What roles can administrators play in implementing the SAFE Program in a rural area?

Select an appropriate staff person to facilitate the program, preferably one with experience working with families dealing with mental illness/PTSD

SAFE Program workshops can be facilitated by a mental health professional (of any discipline). The SAFE Program manual and Toolkit contain clinician-friendly curricula for the 18 sessions as well as detailed information about preparation, documentation, advertising, etc. It’s important for the provider to genuinely understand, respect, and have empathy for the family’s experience of dealing with serious mental illness/PTSD. The provider needs to possess skills in teaching and group facilitation.

Many providers (urban and rural) did not receive formal training in their graduate studies about the impact of mental illness/PTSD on the family. Although VA Central Office is rolling out national trainings on family intervention, the number of participants in such training workshops is very small. Therefore, empowering the provider with support, resources, and access to consultation is essential.

Support the provider in preparing to present the SAFE Program

There are many ways to train and support CBOC providers, including:
• Give them the SAFE Program curriculum (available online at [www.ouhsc.edu/safeprogram](http://www.ouhsc.edu/safeprogram)) and at no-cost by emailing a request to Dr. Michael Kauth at michael.kauth@va.gov.

• Help the provider obtain books about the family experience of mental illness/PTSD. Many excellent resources are noted in the Resource List of the SAFE Program ([http://www.ouhsc.edu/safeprogram/ResourceList.pdf](http://www.ouhsc.edu/safeprogram/ResourceList.pdf)). Although books written for professionals can be useful for providers to review, it can be equally helpful to read books written specifically for families as they often contain practical, helpful, real-life suggestions.

• Urge them to review the SAFE Program Implementation Toolkit ([http://www.ouhsc.edu/safeprogram/ImplementationToolkit.pdf](http://www.ouhsc.edu/safeprogram/ImplementationToolkit.pdf)) that answers many Frequently Asked Questions about program development and implementation.

• Encourage them to attend a workshop or training session held by Dr. Sherman on the SAFE Program.

• Suggest that they explore what other medical centers/CBOCs in their VISN/area are providing the SAFE Program, and see if they can go to observe a session. It can be very useful to learn from other sites’ successes and challenges when creating a program. Each VISN has a Family Education Coordinator who has been trained by Dr. Sherman or Dr. Ursula Bowling in the SAFE program. He/she is a Local Recovery Coordinator (LRC) who is willing to assist other sites in implementing SAFE. Check with your facility’s LRC to find out who that person is for your VISN.

• Encourage the provider to seek out regularly scheduled supervision/problem-solving phone calls with Dr. Sherman, especially during the first few months of SAFE Program implementation. She can be best contacted by email ([michelle.sherman@va.gov](mailto:michelle.sherman@va.gov)). Several clinicians we interviewed expressed the desire for such assistance, and both Dr. Ursula Bowling and Dr. Sherman are happy to provide time-limited support.

• Provide administrative support for publicity (e.g., help in mailing letters, creating and posting flyers, getting articles in newsletters, etc.)

• Ensure that the provider has time in his/her schedule to prepare for and provide the workshops

**How can providers prepare themselves to implement the SAFE Program in a rural area?**

*Familiarize themselves with the unique aspects of their rural culture/community*

Some providers in our study described families living in rural areas as having a unique culture that needs to be understood. Issues to keep in mind include:

• Rural families may be less comfortable reaching out to ask for professional help; they may be more inclined to keep personal matters private. Therefore, providers want to devote considerable time and energy to rapport building, and respect the oftentimes deeply-held values of the family. Extending the invitation to engage in care gently and repeatedly may be useful to help families feel comfortable and to recognize the potential usefulness of services. Providers may find it helpful to describe the SAFE program as a “class” rather than as therapy, as a class format may feel more comfortable and less intimidating.
• Providers need to be mindful that some rural families may hold different beliefs about the cause of mental illness/PTSD. They may have less understanding of the biomedical contribution to serious mental illness (e.g., thinking mental illness is solely due to “weak faith”). It’s important for providers to seek to understand a family’s belief systems and worldview before jumping into a “teaching” mode. Otherwise, even the very best psychoeducational information will be readily dismissed, and families may be discouraged from seeking information/care in the future.

• Rural families may have greater fears of knowing other class members due to the CBOC being located in a small town. Therefore, providers need to spend time and energy addressing confidentiality early and regularly in treatment, specifically exploring how participants would handle situations of previous relationships, meeting in public, knowing the veteran, etc. If providers have any personal experience in living in a rural area, some limited self-disclosure may be useful to convey an understanding of rural culture, especially about the dual relationships that sometimes arise.

Anticipate challenges that may be associated with providing SAFE to families in rural areas and brainstorm possible creative means of overcoming these challenges [Note: This section does not address barriers to participating in family education in general—but focuses on issues associated with families in rural areas]

• Family members do not receive travel pay for coming to VA appointments. For some, even driving to a CBOC is a long distance, so the expense for gasoline may be a prohibitive factor for some families. Family members may lack reliable transportation to make a long trip.

• Similarly, some families who have to drive many miles are unable to take the time off work, due to work inflexibility and/or the resultant loss of income.

• For families who must drive a long distance, the need for childcare can be a barrier. Small children cannot attend the SAFE Program due to their potential disruptiveness and the inappropriateness of their being exposed to some of the discussions. Therefore, providers need to be cognizant of this issue and consider creative options in the local community.

• Some sites choose to offer the SAFE Program in the evenings to allow family members that work to attend. CBOCs choosing to do so would need to ensure that providers are willing to alter their duty hours to work late and that security/police forces are available in the evenings.

How can providers spread the word to rural families about the availability of the SAFE Program?

When providing the SAFE Program in either an urban or rural area, advertising usually requires a large commitment of time and energy. The publicity tips provided in the SAFE Manual apply to rural areas very well. A few additional suggestions were made by rural veterans, families, and providers:

• Tell commanders of veterans groups and service organizations (such as the DAV, VFW, American Legion, PVA) many of whom are active in rural areas. It can be helpful to attend the periodic Vet Council meetings held at VAs and CBOCs.

• Work with local newspapers, radio stations, and television stations to be included in community calendars of events.
• Tell chaplains/ministers/religious leaders in the area about the program.

• Create attractive poster boards to place in clinics.

• Encourage the veteran to bring his/her family member to the next appointment, and discuss the SAFE Program as a team. This allows both the veteran and family member to openly address any fears/concerns/barriers to participation they may have, and for benefits of participation to be emphasized.

• In addition to working closely with other mental health providers, form collaborative relationships with the rural or CBOC primary care providers and nurses. Primary care staff sees a much larger caseload of veterans, many of whom live with mental illness/PTSD but do not seek specialized mental healthcare.

**What logistical issues need to be considered?**

*Mode of provision of the SAFE Program*

The SAFE Program was developed to be provided in a face-to-face group setting. However, several other options could be considered for program delivery. With the growth of available and acceptable telemental health services, providers can consider a range of modes of presenting the SAFE Program, such as using a videoconference, chat rooms on the internet, and conference calls. It may also be possible for a provider with expertise in family education to travel to various CBOCs in an area to facilitate a face-to-face workshop. It is also possible to combine several modes of delivery.

However, all of our veteran and family participants expressed a strong preference for “face to face” groups, expressing concern that other modes would be “impersonal, intimidating, and would not promote friendship.” Providers similarly expressed concerns about providing SAFE via telegroups due to technology limitations (e.g., cannot easily see many group members in various locations simultaneously).

Note: VISNs/CBOC that have telemental health conference units (that can show a group of people on a screen) may wish to consider a slight format modification. It may be possible for a provider at one location to provide the SAFE workshop to participants that are gathered together in one room at another location. While no sites in VISN 16 have this technology at this time, it may be a feasible, practical model to implement as technology becomes available. Although veterans and families in our study expressed considerable reservations about the acceptability of videoconferencing, it’s likely that this service may be much better than not having any programming at all. Also, younger families and families who never had the face-to-face support may be more open to the more sophisticated video options. VISNs/CBOC that choose to use videoconferencing need to think through strategies for handling patient emergencies and for ensuring safety and confidentiality.

*Environment and nature of the location/room (if meeting face-to-face)*

Rural families want a location that is close to their home, safe, quiet, familiar and private. They want to meet in a room large enough so participants can sit in a circle and comfortably interact. You may wish to consider the CBOC itself (if a sufficiently large room exists), a service organization post or armory, a church or other
Role of the veterans

The SAFE Program is designed specifically for adult family members/friends who care about someone living with mental illness/PTSD, and veterans are not included in the sessions (see the SAFE manual for more information on the rationale). Other family programs exist that provide joint sessions for veterans and families.

However, some sites have developed creative ways of overcoming some of the challenges associated with family members coming alone. The SAFE Program may be offered at the same time as another program held for veterans. For example, the SAFE Program could be provided while a separate, large PTSD group is being held for veterans. This could allow veterans and families to travel to the CBOC together, overcoming challenges of the lack of travel pay for families and gasoline costs. The pros and cons of offering concurrent veteran groups and SAFE would need to be explored at each site.

What can CBOCs do if the need for more intensive/specific family services becomes evident during a SAFE Program session?

Many CBOCs do not have the staffing to provide a wide range of family services, such as couples/family therapy and parent training. Therefore, it’s important for each CBOC to know what nearby CBOCs, VAMCS, Vet Centers, and community providers offer and to develop a list of community resources to which local families can be referred. Common referrals would be for couples/family therapy, individual therapy for the family member, assessment and therapy for children, and domestic violence treatment. It would be very important to tell family members wishing to seek these services in the private sector/community that doing so would be at their own expense.

We would love to hear about your experiences in providing SAFE in a rural/CBOC setting.

If you are willing to share, please contact Dr. Sherman at Michelle.Sherman@va.gov OR 405-456-5171.

We would like to learn from you—and, in turn, be able to support other sites in developing family education for rural veterans.

Special thanks to the VA Central Office of Rural Health (ORH) and the South Central Mental Illness Research, Education and Clinical Center (MIRECC) for their support of this project.
Resources for Global War on Terrorism
Military Families
Compiled by Michelle D. Sherman, Ph.D. (Revised March 2009)

BOOKS

For Veterans / Service Members (and Adult family members)


For Kids


_A Very Long Time_ (2005). [for kids ages 4-8; picture book for children whose parent is deployed]. Geri Timperley, Nikki Arro


WEBSITES

Military OneSource (1-800-342-9647).  www.militaryonesource.com

Military HOMEFRONT (Official DoD site).  www.militaryhomefront.dod.mil


Strategic Outreach to Families of All Reservists:  www.sofarusa.org

US Department of Veterans Affairs:  www.va.gov  and  www.oefoif.va.gov

State Departments of Veterans Affairs:  www.nasdva.com

Vet Centers:  www.vetcenter.va.gov

National Resource Directory:  www.nationalresourcedirectory.org

**Emotional Health:**

National Center for PTSD.  www.ncptsd.org

National Mental Health Association.  www.nmha.org/reunions

S.A.F.E. Program, Support And Family Education: Mental Health Facts for Families. An 18-session curriculum for people who care about someone who has a mental illness / PTSD.  w3.ouhsc.edu/safeprogram

Mental Health Self-Assessment Program (DOD sponsored mental health / alcohol screening and referral program offered to families and service members affected by deployment)  www.MilitaryMentalHealth.org

**Deployment:**

After Deployment:  www.afterdeployment.org/index.php

Surviving Deployment: Resources for Military Families.  www.survivingdeployment.com


**Issues about Children/Youth**

*For Kids:*

National Guard Family Program / Guard Family Youth Website  
www.guardfamily.org // www.guardfamilyyouth.org

VA Kids: www.va.gov/kids

Army Reserve Child and Youth Service’s Online Teen Deployment Class  

My Life: A Kid’s Journal (for during deployment- by Health Net Federal Services)  

*For Parents and Educators:*


Military Child Education Coalition  
www.militarychild.org

Operation Child Care (for National Guard and Reservists).  
www.childcareaware.org/en/operationchildcare

DOD’s Military Student Program: The Military Child in Transition and Deployment  
www.militarystudent.dod.mil

http://nctsnav.do?pid=ctr_top_military

www.aacap.org/cs/root/facts_for_families/coming_home_adjustments_for_military_families  
http://www.aacap.org/cs/root/facts_for_families/families_in_the_military

https://www.operationmilitarykids.org/resources/ToughTopics%20BookletFINAL.pdf

http://jhsph.edu/mci/training_course

Military Kids Bill of Rights  
10 Things Military Kids Want You to Know

Salute Our Services A Thousand Thanks to Military Kids Program (sends free personalized card to military child): [website link]

VIDEOS

*Talk, Listen, Connect: Deployments, Homecomings, Changes.* Sesame Street DVDs for families with youth ages 2-5. Available for free through Military OneSource (1-800-342-9647) OR [website link]

*When Parents Are Deployed* (with Cuba Gooding, Jr). Sesame Street video. Available to view at: [website link]


*Getting Home: All the Way Home.* Free downloadable DVD created by TriWest (TRICARE Contractor) for soldiers & their families. [website link]

*Young Children on the Homefront,* ZERO TO THREE. Military families share their unique deployment experiences and professionals offer tips and strategies for dealing with difficult issues such as grief and loss from deployment and the challenges that often arise upon reunification. Available to view at: [website link]

*Young Heroes: Military Deployment Through the Eyes of Youth.* 18 minute video created by teens of the New Jersey Operation Military Kids’ Speak out for Military Kids Program explaining the deployment cycle: [website link]

*The Price of Peace.* Song by two military teens about deployment. [website link]