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. And that dream is shattered” (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
- helpfulness
- 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:**
  - Family
  - Consumer

- **High Potential for Burnout and Loss of Self:**
  - 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.