CLASS 9

ADDITIONAL RESOURCES

Take Care of the Caregiver

Dedicated to those family members and friends who are primary caregivers of a loved one or friend with mental illness...

1. Be gentle with yourself.
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 about you—and learn to accept it in return.
5. Remember that in the 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 in caring and in 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 the complaining that reinforces it.
8. On your way home from work, 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 to redirect yourself.
11. Avoid “shop talk” during your breaks or when you are socializing with colleagues.
12. Learn to use the expression “I choose to...” rather than expressions like “I have to...,” “I ought to...,”or “I should...”
13. Learn to say, “I won’t...” rather than “I can’t...”
14. Learn to say “no” and mean it. If you can’t say “no”—what is your “yes” worth?
15. Aloofness and indifference are far more harmful than admitting to an inability to do more.
16. Above all else—learn to laugh and to play.

–Author Unknown

Symptoms of Inner Peace

1. Tendency to think and act spontaneously rather than from fears based on experiences from the past.
2. The ability to enjoy each moment.
3. Loss of interest in judging self.
4. Loss of interest in judging other people.
5. Loss of interest in conflict.
6. Disinterest in interpreting actions of others.
7. Loss of ability to worry.
8. Frequent episodes of appreciation.
9. Contented feeling of connectedness with others and nature.
10. Frequent attacks of smiling through the eyes of the heart.
11. Increasing susceptibility to love extended by others as well as the uncontrollable urge to extend it.
12. Increasing tendency to let things happen rather than to make them happen.

If you have all, or even most of the above symptoms, your condition of peace may be so far advanced as not to be treatable.

What Caring Adults Can Do for the Child whose Parent has a Mental Illness

by Cathy Aines, Former Executive Director, NAMI-Vermont

1. Tell the child what illness their parent has, its symptoms and prognosis. Discuss the medications their parent will be taking. Give them as much information at an age appropriate level, as they seem to want to have. It is very frightening to be kept in the dark.

2. Give the child frequent opportunities to discuss his/her fears, questions and concerns.

3. Listen to the child without judgment. Assure the child that all of his/her feelings are valid and okay.

4. Make reading material available. For a young child, reading together creates a positive atmosphere for further discussion and questions. But for the older child, leave the material in an accessible place and allow the child to read when they are ready. Don’t push or question. The child may be uncomfortable talking about the subject (or feel disloyal to the ill parent).

5. Whenever possible, allow the child to participate in decisions that affect the whole family.

6. Create opportunities for the family to be “normal.” For example: Going to church together, taking a vacation or holiday, going school shopping. It is difficult to feel “normal” when your parent has mental illness.

7. Recognize the child’s accomplishments in school, sports, music, etc. Encourage the child to participate in activities that are important to them personally and to develop their own talents.

8. Let the child know that it’s okay to have fun, that their ill parent would want them to have a normal, happy life in spite of the family situation.

9. Assign the child an appropriate level of responsibility in the care of the home, other siblings and the ill parent. Children can be so anxious to help that they will take on an overwhelming burden of responsibility. It is up to the adults in their life to know how much is too much.

10. See that the child understands that no matter what care-taking role he/she has, the child is in no way responsible for the onset of the illness, its symptoms, severity or ultimate outcome. No child can control mental illness, but many believe that they can if only they work hard enough at it.

11. Share the work to be done among all siblings, according to their ability to participate. Too often one child becomes the caretaker. All children need to feel involved.

12. If the parent is hospitalized, give the child the option to visit or not. Psychiatric wards and state hospitals can be very frightening to a child. They are exposed to other very ill patients besides their own parent, not to mention barred windows, locks and fences.

13. If your child chooses to visit, prepare him/her in advance as to what to expect. Explain what they will see and why. Talk about it afterwards.

14. Talk about what happens in the hospital, the treatment their parent will receive, how long they will be hospitalized, what to expect when the parent returns home. Be realistic.

15. A talk with the parent’s doctor may be reassuring for the older child. Also, it may give the child an opportunity to ask questions that they would hesitate to ask a parent.

16. Take steps to ensure the safety of the child at all times. While most persons with mental illness are not violent, the unpredictability of the illness may make the child feel threatened. A child experiences so much guilt about even having this fear of their own parent that he/she is not likely to mention it. Make arrangements for the child before and after school and give serious thought before utilizing a child as a sitter for the mentally ill parent.

17. Learn coping skills as a family. There are more effective ways to communicate with a person with psychosis. Help the child with this.

18. As a parent recovers from a psychotic break, there is a readjustment and reintegration into the family. The older child may have difficulty accepting the return of “Mom” or “Dad.” Talk this out as a family. Recognize how this will impact the children in the family.

19. Make sure that the family is represented at the child’s important occasions such as graduations, religious ceremonies and recitals.

20. If there is a peer group in your area for children with mental ill parents, encourage the child to join.

21. Offer physical affection regularly. A hug or a smile may be really needed.

22. Foster a sense of humor. Mental illness is serious and tragic, but a sense of humor can be a valuable tool for coping with the bizarre behaviors that accompany delusions and hallucinations.

16 Pointers to Help a Spouse Live with Mental Illness

by Kathy Bayes & Spouse Support Group

1. The mental illness your spouse suffers with is something that is happening to your entire family. All are affected and it is nobody's fault. It is not your fault, your spouse's or your children's fault. It is an unfortunate illness.

2. You cannot fix your spouse. There is nothing you can do to make him or her well, so don't feel compelled to try. What you can do is be supportive, loving and handle the everyday details and practical issues of life for him that he or she cannot cope with.

3. All members of the family have a responsibility to cope with the illness. Escape is not a helpful way of dealing with the crisis. You all need each other.

4. The ill spouse must recognize and accept the illness, be willing to receive treatment, and if possible learn to manage the illness. If the ill spouse is not willing to do these things, it may become impossible for the family to continue to support him or her. The family is not required to throw away their own lives for someone who refuses to cooperate. There are limits, and they must be enforced without feelings of guilt.

5. Educate yourself concerning every aspect of the illness. Education brings compassion. Ignorance just encourages anger and fear.

6. Grieve your loss. It is a great loss. You need to allow yourself to experience the entire process of grieving.

7. Get help for yourself to cope with this incredible challenge, either from your own counseling sessions, or a NAMI support group. You can't do it alone. Don't refuse to recognize your own need for help, just because the ill spouse is getting most of the attention.

8. Help your children understand the illness as much as their age allows. NO FAMILY SECRETS. Don't deny them the opportunity to learn about the illness, the unfair stigma attached to it, and developing their own skills in coping. It can be an incredible learning opportunity for them. If they need professional help to understand it and their own feelings, get it for them.

9. Try to create a safe environment for the spouse to express himself without feeling threatened, constrained or condemned. He desperately needs a nurturing, safe place to express the incredible frustration he or she is feeling about this illness.

10. You and your children need to share your feelings honestly and openly. It's o.k. to feel angry and cheated. At times, you may feel embarrassed by the ill spouse's behavior. Avoid trying to protect your spouse by not discussing the problem with family members or friends. Don't require your children to conspire with you in a code

of “family secrecy.” Family secrets will isolate you from others. Remember that small children, by their very nature, assume that they are responsible for anything in their environment that goes wrong.

11. Never put yourself or your children in physical danger. If you sense your spouse is becoming dangerous, you should leave and call for professional help. You should never tolerate abuse of you or your children! Trust your instincts and intuitions on this one. Say no way, and mean it.

12. Become your spouse’s advocate with the medical professionals, assertively involved in his treatment and medication. If the medical professional or psychiatrist won’t cooperate with you, demand a different one! Stand your ground assertively, but try not to be a pain in the neck. Treatment should involve the entire family, so find a professional who will work with the whole family. You know more about your spouse’s illness than anyone else. Trust your instincts.

13. Coldly assess what your spouse can and cannot handle, then compensate assertively. Some people with mental illness cannot handle money, some household chores, time commitments, or too much stress. You must not do things for your spouse that he or she can do for themselves. Don’t rob him of his dignity.

14. Maintain your own identity; resist becoming consumed with this illness. Life goes on. You have an obligation to yourself and your children to take care of yourself and meet your own needs. We all must continue to develop our own interests and talents. You are a valuable human being, so don’t play the martyr role and sacrifice yourself. That’s just self-pity; “get a life.”

15. Always hope for healing. The medications do work and new ones are being developed. You may get your spouse back whole someday. If nothing else, the experience will broaden and deepen you in ways you never imagined. You CAN be a better person for it. Or you can choose to let it destroy you and your family. It is your choice.

16. Keep in mind that bad things happen to almost anyone, and you’re no exception. You have not been singled out for special persecution. Trying to make good choices in life won’t protect you from misfortune. You haven’t been “dumb” to “get yourself in this situation.” It is not your fault. Life is not easy. We have to take what we get and make the best of it.

How Providers Can Help Siblings, Adult Children and Partners/Spouses

The following information represents a composite of responses from family members who have participated in NAMI Family-to-Family In-Service Training programs, given around the country, to introduce professional providers to the “Relative Groups” in families of individuals with mental illness.

How Providers Can Help Siblings:

Many siblings want providers to listen to them, to ask what they know, think and feel about their ill sister or brother, to let them be involved constructively by helping in some way.

Siblings also need providers to understand and support them when they feel they must step out of the family problem, to empathize when they are torn between the things they need to do to move their own life along and the obligation they feel to help their parents and their ill brother or sister.

Sibling’s survival guilt can arouse many fears about their own mental wellbeing, and influence many of their decisions about life choices. These issues are very real for young adult siblings who are just starting out into the world; they need to talk about these feelings and to explore whether their sibling’s illness might be casting a shadow on any part of their lives.

Oddly enough, many siblings report that providers (and even people in their own families) do not register the enormity of sibling loss, or comprehend the depth of sibling grief. Perhaps this is part of family denial, of parents not wanting to see any more “hurt” children in their family. Perhaps it is the way people neglect survivors’ feelings because, after all, they have been lucky enough to survive. Sibling loss is normally intense and is reactivated at every developmental milestone throughout life. Providers can help sibs with the grieving process at any one of these points.

Siblings tell us that they have commonly blocked the trauma of scenes and events that they witnessed then their brother or sister was critically ill. This includes traumatic things that happened to them, like being threatened or abused. Providers need to understand that siblings who have endured these ordeals often want to detach from the ill sibling, and regard them as hateful and frightening. With education and support, the well sibling can come to understand that these behaviors are illness-related, but it takes time and courage to overcome this kind of trauma.

Many siblings report that they feel invisible in their family after mental illness strikes—that their needs get lost in the intense demands made on the family by their ill brother or sister. Siblings in these families must bear witness to the extraordinary stresses imposed on their parents and often do not want to burden their parents further with demands of their own. Sibling support groups provide a safe and welcome place for well siblings to talk about these issues.

How Providers Can Help Adult Children:

The vast majority of people who are the children of individuals with mental illness do not develop mental illness themselves. It is important for providers to de-stereotype this population, which has often been portrayed as inescapably disordered due to parental dysfunction. Each adult child will have his/her unique story to tell, and should not be negatively “categorized” due to the circumstances of mental illness in a parent.

However, most adult children will tell you that no one can come through this experience unscathed. Depression, anxiety, feelings of hopelessness and defeat, repressed anger, magical thinking, and passivity all combine to form a persistent dysthymia that can rob life of happiness. Many adult children appear to be exceptionally self-reliant and competent, masking the conflict they have about dependency needs and their reluctance to ask for help; rarely do they allow others to glimpse the sadness and uncertainty they feel inside. Adult children can be greatly assisted by psychotherapy; special support groups are now available, as are educational and self-help books relevant to their family experience.

Studies indicate that having a well parent in the mix, or a sustaining sibling relationship, will mediate the stress involved in coping with an ill mother or father. Without these supports, life for the child is often terrifying and traumatic, and worse if the family must endure the more severe spectrum of illness. Children caught in this situation need networks of support outside the family, and must be helped to create a psychological buffer between themselves and the disordered behavior of their ill parent.

Adult children mourn the loss of their childhood, the loss of a carefree, stable family structure, and the loss of their own young potentials. Many children coming through this hardship are “late-bloomers”; so much of their development and self-confidence is placed on hold while they cope with the disabilities of the parent. Others speak movingly about how odd it feels to outgrow a parent, to develop beyond the capacities of a person you always expected to be “ahead” of you, showing the way. Many report a sense of dread at the prospect of “signing- on” again to care for the ill parent as the parent becomes older. These conflicts and ambivalences need to be treated with empathy and respect.

Many adult children relate that they were told nothing about what was wrong with their ill parent—that even after growing to adulthood, they are still “in the dark” about the parent’s diagnosis. It is paramount for mental health professionals to provide education and guidance to children, to help them identify illness behaviors and to consult with them about family decisions made to accommodate the ill parent.

The most important role for providers in helping children of a parent with mental illness is a preventive one—that is, giving the parent sufficient services and supports to keep the illness (and the family) stable. Whenever children are involved in a family with a parent with a serious psychiatric illness, the family should be offered supportive family consultation and family education.

How Providers Can Help Partners/Spouses:

Partners/spouses report that they have suffered greatly from neglect from service providers. They universally testify that they need and want information about their partner's illness and help in coping with it. They want this information to be practical and honest; it should cover topics of illness management, sexuality, single parenting, money management, economic hardship, and handling the withdrawal and/or excesses in their husbands' or wives' mental illness behaviors.

Partners/spouses need to confess their ambivalence about staying in the marriage (which is a normative conflict), without being made to feel that they are disloyal to their partner. They need to talk about their loneliness, their isolation and their emotional hardship without fearing that they will be blamed.

The partner/spouse relationship is the only close family relationship which is chosen and can be terminated by divorce. This means that well spouses will be faced with agonizing uncertainty about how to weigh their own life needs against those of the ill partner. Partners/spouses feel terrible when a provider tells them to "Get out of the marriage" or conversely, that it is "their duty" to stay with the marriage.

Partners/spouses don't want their single-handed efforts to hold their family together to be misinterpreted as "infantilizing" their partner/spouse, or to be tagged as the "cause" of their partner/spouse's difficulties. Wives particularly complain that providers negatively stereotype them as "over-productive" partners bent on wrecking their husband's masculinity.

Partners/spouses need to be encouraged to build a life outside the home, through work and through rewarding social and community activities, which may or may not include the ill partner/spouse. Meaningful work and friendships outside the family are great bulwarks against stress and caregiver burnout.

Most of the pressures on the well partner/spouse are missed because of the erroneous assumption that "other than the illness," the family is doing fine. It is more realistic for providers to assume that the family is not doing fine—that the community may have stigmatized them, that the in-laws are probably blaming the well partner/spouse, that the children need support, education and assistance, that the marriage is suffering due to a lack of mutuality and emotional reciprocity, etc.

Partners/spouses need help in identifying and establishing a reliable network of support. This involves helping a partner/spouse learn to ask key people for certain specific things—friendship, commiseration, assistance with the kids, advocacy for services, or even help with finances when the going gets rough.