

Supportive Family Training

Working Through the Heart: A Transpersonal Approach to Family Support and Education

By Sheila Shulman Le Gacy (reprinted with permission)

Published by Psychiatric Rehabilitation Journal

Sheila Shulman Le Gacy, MA, the creator of Supportive Family Training, is the Director of the Family Support & Education Center at a not-for-profit rehabilitation and residential agency in Syracuse, New York. She served for 8 years on the board of NAMI New York State, and presently coordinates NAMI curriculum and training for upstate New York. For further information contact the author at Transitional Living Services, 239 W. Fayette Street, Syracuse, NY 13202, 315-478-4151 office ext152.

The following article by Sheila Shulman LeGacy was originally published in Psychiatric Rehabilitation Journal, www.bu.edu/sarpsych 1998, Vol. 22, No. 2.

Supportive Family Training is designed for the relatives of persons diagnosed with serious psychiatric disorders. Support, education, and advocacy is the three-point focus of the training, which provides the framework for a powerful and cost-effective teaching model. Supportive Family Training presents the latest research about schizophrenia and the major mood disorders, and provides practical coping and management skills, communication techniques, and problem solving. In addition to receiving extensive information about their relatives' illnesses, and support for their pain, families are given effective strategies and language to assist them in communicating with mental health professionals. The model allows for a limited number of mental health professionals to enroll in the course, with the goal of providing opportunities for professionals to empathize with the family experience and for the families to understand the perspectives of professionals.

In this article I describe an approach to family support and education that actively focuses on the suffering endured by families who have relatives with neurobiological brain disorders. I have been

teaching families for over 17 years. I also have a close relative with schizophrenia. The hundreds of families that I have worked with, and my own experience, have convinced me that family support and education is at its most effective when it is built upon a conscious and compassionate acknowledgment of the pain that is inherent to this particular caregiving experience. I believe that until families accept, and learn to manage, the spectrum of powerfully charged and painful emotions they experience, they cannot be free.

My own experience with a family member who has schizophrenia has greatly influenced my work. In this way I have benefitted from being part of the lineage of family member/professionals like Hatfield (1990), Lefley (1987), Terkelsen (1983) and others whose experiential knowledge has informed their writing and brought common sense to a field that desperately needed it—and still does. Direct experience is a great teacher. I have acquired coping skills that I now share with the families I work with. Having learned through difficult personal experience that the most effective way out of pain is by going through it, I openly confront the issue of suffering and offer families techniques for working through it.

One of the first lessons family members must learn is to separate the pain they feel for their relatives with mental illness from the pain they are feeling for themselves. Some family members, especially parents, are so acutely tuned into their relative's pain that they haven't dared enter into their own. Once they are able to get in touch with their own pain, however—to enter this pain and work through it—they gain the strength that enables them to accept their relatives with mental illness as they are, not as they wish they could be. It is only at this point that family members can begin to truly address their own needs. And this is the focus of Supportive Family Training (SFT), the short-term (12- week) course I designed and in which I include practical techniques that can be easily integrated into a variety of family interventions. “Although families have been tending to ill relatives for centuries, this is the first era in which we are beginning to develop a technology focusing on the needs of caregivers as distinct from the needs of patients” (Lefley, 1987 p. 92). My intention is that this article and the outcome data on SFT (Horgan, 1995) will contribute to that technology and to the kind of “effectiveness research conducted under natural service circumstances” that Solomon (1996, p. 1367) recommends.

The techniques that I teach are grounded in a transpersonal framework. I use the term transpersonal to mean “beyond the self” or “larger than self.” The goal of the transpersonal approach is to free the energy of individuals who suffer by connecting them to the pain of the world. It may seem a paradox that connecting individual pain to the world’s pain decreases suffering, but it can and it often does. Normalizing pain makes it more bearable.

When we see the suffering in the world around us, we begin to understand suffering not only as an individual problem but as a universal experience, as one of the aspects of being alive. (Macy, 1991, p. 42)

People are hungry for connection and meaning in their lives, and sometimes painful experiences, like the wrenching loss and grief experienced by the families of individuals afflicted with serious neurobiological brain disorders, provide opportunities for making that connection.

Eric Cassel, MD, (1982) eloquently addressed the transpersonal dimension:

Transcendence is probably the most powerful way in which one is restored to wholeness after an injury to personhood. When it is experienced, transcendence locates the person in a far larger landscape. The sufferer is not isolated by pain but is brought closer to a transpersonal source of meaning and to the human community that shares these meanings. Such an experience need not involve religion in any formal sense; however, in its transpersonal dimension, it is deeply spiritual. (pp. 639–644)

I feel that this is an opportune time to take family work to a deeper, more spiritual level. I characterize the Supportive Family Training methodology as a way of “working through the heart.” The transpersonal perspective on which the training is based allows for methods that extend family education more deeply into the emotional and spiritual realm than do conventional family interventions.

I also want to share my teaching experience in order to inspire and encourage other professionals to do this work. Sometimes, the “helping professions” do not really help all that much, and human

service professionals lose heart and energy, and the hope that they can make a difference. By offering an intervention that allows family members to make significant changes in their own lives and in the ways they relate to their ill relatives, you actually see how the help you provide serves to free the energy of those who suffer, and you, yourself, benefit from that energy. Successful work with the families of persons with psychiatric disabilities can be a very powerful and inspiring experience.

By focusing on the needs of the family foremost, my approach differs from psychoeducation, which explicitly begins with patient needs (Dixon & Lehman, 1995). The primary objectives of SFT are to reduce family burden and to enhance their quality of life. Impressing families with the importance of self-care, as well as teaching them basic coping skills and problem solving, are means to these ends. I speak to families on several levels. Working with emotions, for example, is given equal status with discussing the causes and treatments of the schizophrenias and affective disorders. I also draw on a wide variety of techniques from adult education, peer counseling, stress reduction, meditation, yoga, bereavement work, and advocacy training. In short, families are taught methods to care for their own needs at the same time that they learn to become more effective advocates for their ill relatives.

And though I concentrate on working with caregivers, as the name Supportive Family Training implies, my long-term goal is to ease the burden for all members of the family, most particularly the person with the neurobiological brain disorder. My essential message to caregivers is that by attending to their own needs, they better serve the needs of their loved ones and the family as a whole. Any rational systems approach would support the view that once their own well-being increases, families will become more successful at dealing with their relatives. I have observed, for example, that when parents begin to take better care of themselves, the behavior of their adult offspring sometimes improves. On the other side, many individuals with mental illness are very conscious of the pain they have brought to their families. Their guilt at seeing their families depressed only adds to their burden. They often feel better when they see family members tending to their own needs.

Limits of Current Research

Although clinically oriented psychoeducational programs have been well researched (Dixon & Lehman, 1985), there has been little formally controlled research on family education programs. Solomon's (1996) report on five rigorously designed evaluations of family education programs showed no consistent outcomes. Measures of rehospitalization and relapse rates have been the sacred cows in most studies attempting to quantify the effectiveness of psychoeducational programs for families. But, as Solomon noted, "relapse" as a major indicator of treatment effectiveness may not be appropriate for time-limited family education interventions. Also, this measure may sometimes be irrelevant and/or misleading in the context of the family. For instance, I frequently work with families who do not live with their ill relatives and/or have limited contact with them. The relapse rates of the relatives of these families are independent of their interactions with kin. I have also observed that families trained to be effective advocates are often more successful at obtaining services for their relatives. As a consequence, hospitalizations of their relatives may increase over the short term, an outcome that confuses the picture unless data are factored in showing that the relatives of effective advocates get better treatment than people without family support.

Because of the constraints of research design, many of the psychoeducational programs that have been studied were limited to the relatives of persons with schizophrenia (McFarlane, Dunna, Lukens, et al. 1993). In what Solomon (1996) describes as the "natural service circumstance" that I work in, combining, in one class, the families of persons with mood disorders, obsessive-compulsive disorders, schizophrenia, and other disabling psychiatric conditions works quite effectively.

Researchers (Dixon & Lehman, 1995) have suggested that nonclinical family interventions may be more effective at helping families than at lowering patient relapse rates. We do not know, however, to what extent this may be true. If improved patient outcomes are the ultimate goal, nonclinical approaches such as those discussed here may arrive at the same place, but perhaps by different routes.

Recent research does indicate, however, that models like SFT, which combine engagement, support, and problem solving, and education, are superior to brief psychoeducation alone (Dixon & Lehman, 1995; Solomon, 1996). It has also been my experience that these models of family education and support, which are explicitly focused on family needs, are not only cost-effective but are more attractive to families because they are less stigmatizing and isolating than clinical treatment. Most of these approaches offer what I consider to be a critically important advantage—teaching advocacy and linking families to advocacy groups, such as the NAMI, which provide ongoing support. Questions raised by these and other observations require further study. Clearly, more work needs to be done to describe the essential elements of family interventions and to respond to “the host of unanswered questions” raised by Solomon (1996). Hatfield’s (1994) suggestion that quality-of-life measures be part of future research on family interventions is certainly on track.

The Need for Combining Head Knowledge and Heart Knowledge

I believe that there are two effective ways of reaching people: through their minds and through their hearts, and that combining both approaches is more powerful than using one of them alone. Conventional educational techniques and objectives are clearly needed. SFT, for instance, is based on a 500-page, carefully scripted manual of continually updated information about the causes and treatment of the schizophrenias and affective disorders. Families are hungry for information, and education is clearly empowering. Comments like the following are routine: “I learned more about my daughter’s illness in 12 weeks of this class than I’ve learned from 12 years of speaking to psychiatrists and social workers.”

But the conventional goals and techniques of education do not go far enough. Families need both head knowledge and heart knowledge. Certainly they need to accommodate themselves to the facts surrounding mental illness, but it is not enough for them to learn that their relative is indeed suffering from a legitimate illness whose symptoms may persist for many years, sometimes forever. Nor is it sufficient for them to lower their expectations for their family member’s return to previous levels of functioning. These are only the first of many important steps that families must take in the path to acceptance. In my experience individual family members make real breakthroughs when they are able to confront their pain around the illness of their loved ones on a

deeper level than that encountered in conventional family educational programs. And yes, for most families, the work gets harder when they are asked to go deeper into their sorrow. The most important and the most difficult work for families is facing the pain and grief of what will not be. When they get in touch with this reality, and stop pushing it away, they become stronger. As a participant in one of my classes recognized:

The answer doesn't lie in learning how to protect yourself from life. It lies in learning how to strengthen yourself so you can let a bit more of it in.

SFT: The Critical First Interview

My initial contact with a family usually begins with an hour or longer interview during which I learn the history of their relative's illness, discover how they have been dealing with their situations, and ask how I can be of help. This intake interview is a critical step in enrolling families in the classes that I teach. I believe that it is partly responsible for the fact that in over 17 years of teaching SFT, no family member has ever dropped out of the course, except for illness or relocation. During one recent interview, a mother expressed her reluctance to open herself up to the painful feelings she felt the classes might subject her to. "I have built this nice wall around myself," she said, "and I am afraid of what would happen if I let it down." Her coping style was very familiar. I have encountered many family members who hold everything in, and who are so tightly controlled that one imagines they fear that letting in one soft feeling would break down the wall of defense they have built against their pain. I cannot emphasize too much how intense this pain can be. Lefley's (1987) comment, "watching the 'known personality' decompensate is terrifying for the family, who can never be prepared for this experience," comes close to giving the feeling tone of "this existential crisis, devastating in its impact."(p. 47).

Defending Against the Pain

The concept of high expressed emotion (high e.e.), as measured by criticism, hostility, and emotional over-involvement, invariably enters into discussions of family interactions with their relatives with mental illness. I believe that much of the high e.e. behavior manifested by some families, especially critical comments, comes not from just an ignorance of the nature of their

relative's disorder, but also from defending against their own painful feelings, especially feelings of grief. I believe that this aspect of the high expressed emotion issue has not been sufficiently examined in the literature. Grief can be expressed in many different ways. Sometimes it does not look like grief might be expected to look. Sometimes it may be expressed as anger, or as criticism. As a mother in one of my classes explained: "Anger is sometimes a protection against helplessness and emptiness. It makes me feel temporarily less vulnerable—at least for a little while." Many therapists reading these words would see these defenses people use as clinical issues. But, as Lefley (1994) points out, even though working with emotions is supposed to be the work of psychotherapy, "paradoxically...education that is family focused may deal with emotions more effectively than patient-focused therapeutic approaches aimed at lowering e.e." (p. 94). Furthermore, the success of bereavement groups indicates that families can learn to deal with grief and loss very effectively outside of a clinical context.

Grief

Researchers have found higher levels of acute and ongoing grief in families with a mentally ill child than in families whose child has died. The families studied included children with chronic depression, bipolar disorder, schizophrenia, or a personality disorder (Atkinson, 1994).

A reluctance to acknowledge the universality of suffering, of grief, and of loss appears to be particularly American. Powerful images from the media and advertising reflect many of our cultural assumptions that feeling pain or sadness is weak, shameful, and humiliating—that somehow we should be able to control our pain or our feelings of loss. As a result, feeling sorrow carries an added burden in our country: one feels bad about feeling bad (Macy, 1991). By encouraging material consumption and painkillers as ways to avoid suffering, American culture supports our need to insulate ourselves from pain. The problem is that when we experience painful feelings, we often feel isolated and disconnected from the rest of the world just at the point when we most need to be connected (Salzberg, 1995). These persistent messages makes it very hard for people to recognize that many forms of suffering are normal and healthy. The original, literal meaning of pathology is the study of suffering; it held no connotation that suffering itself was wrong or sick (Macy, 1983).

I speak often to families about the necessity to acknowledge their pain, and how pushing it away is counterproductive. I have found it helpful to cite a distinction that the teachings of Buddhism make between pain and suffering, which points out that the two are not inevitably linked. Buddhism holds that pain is part of life, and that suffering comes from the denial or avoidance of pain.

Pain is one thing, and resistance to the pain is something else, and when the two come together you have an experience of suffering. Whenever there is resistance, there is suffering. As soon as you can see that, you gain an insight into the nature of pain and as you gain that insight, you'll begin to have some freedom (Young, 1994).

MacGregor (1994) has described how parents of people with mental illness go through the same general phases of grief that parents travel through when they lose a child to death. The difference is that the parents of an individual with mental illness are at risk of “disenfranchised grief” because their loss is not “openly acknowledged, publicly mourned, or socially supported” (Doka, 1989, p. 4). Their painful emotional responses to their loss and to the stress of chronic caregiving are often misinterpreted, ignored, or pathologized by professionals who have traditionally been trained to look for disorders, and to interpret pain as a symptom of malfunction (Cassel, 1982; MacGregor, 1994). “What is currently experienced by most parents of the mentally ill could be considered almost a worst-case scenario which practically assures unacknowledged and disenfranchised grief” (MacGregor, 1992, p. 11).

A couple who lost two sons, one in an automobile accident, and one to schizophrenia, used to come to my class on the Wednesday following the Tuesday they attended a support group for the bereaved. The mother said that her pain for her son who had died was like a wound that had healed over—there would always be a scar but it was fading. Her pain, however, for her son with schizophrenia was like an open wound that had never healed. She came to us to work on the healing. This mother was not unique. I have heard many family members express similar feelings, very much like MacGregor's (1992) poignant quote from a mother of a son with manic depression: “It's as though our son dies every two years” (p. 6).

Grief Work

Grief is a normal, healthy, spontaneous, and necessary response to loss. Moving through the process of grief and mourning toward some kind of resolution is hard, painful, and sometimes frightening. (MacGregor, 1994, p. 163–164)

This process, called “grief work,” involves acknowledging the full measure of pain you feel, in whatever way it manifests. Grieving is not only a process of coming to accept loss, but grieving, in itself, is a kind of healing. Once grief is no longer the central issue, other growth is possible.

It is not easy for many family members to fully admit to their anger and grief over a loved one’s illness and to acknowledge what it has done to their lives. Sometimes it takes real work for them to access those feelings. To bring grief issues out into the open, I frequently use examples from my own experience, using a transpersonal perspective—the sense of shared suffering—as my guide. I begin by acknowledging the personal quality of a family’s pain. Although there are important differences in the ways siblings, fathers, mothers, adult offspring, spouses, and grandparents respond, all of these relatives experience the added burden of stigma, a burden unique to these families. Paradoxically, perhaps, getting into the specificity of their pain and the seeming uniqueness of their situation eventually links them to the universality of suffering. It is through this process that families discover there is nothing special about their pain. Pain is pain. It helps to know the details but the particulars do not make the general any less true. Once families grasp this, they begin to feel less isolated, and more complete, more connected, and, in time, more hopeful.

The support provided by the group is very healing and, as Spaniol and colleagues (Spaniol, Zipple & Lockwood, 1993) have observed, hearing other families disclose their pain gives each participant genuine insight and a powerful incentive to work through their own grief. The group truly grieves together. This group process is very powerful and very necessary because, as MacGregor (1994) has noted, grieving is a social event; grief work cannot be done in isolation.

Grief is intense, but it does not have to go on forever. Lindemann’s (1945) successful short-term treatment demonstrates that, once persuaded to yield to the grief process, an individual can

change in a relatively short time. Supportive Family Training incorporates all the steps that Lindemann considered necessary to the grieving process, steps he maintained could be accomplished in eight to ten interviews:

He will have to express his sorrow and sense of loss, find an acceptable formulation of his future relationship(s) ... verbalize his feelings of guilt, and find persons around him whom he can use as "primers" for the acquisition of new patterns of conduct. (p. 147)

The truth, as McGregor (1994) wisely concludes, is that serious mental illness can represent a tragedy to a family, but it does not have to be an unending tragedy. Times of loss offer everyone the opportunity to deepen emotionally, to grow in maturity, to experience spiritual healing, and to connect with one another as human beings.

Self-Care

Because of the demands of caregiving, many families have severely neglected their own needs. Some family members have put their own lives "on hold"; some feel that it is selfish for them even to think of their own needs. This attitude is particularly true of mothers, and especially the cohort of women who became mothers before the 1960s, when maternal self-sacrifice was the order of the day. But, even in the nineties, it is common for fathers, siblings, and adult offspring also to feel this way.

This is why I address the importance of self-care from my very first meeting with families, and why I continue to emphasize it throughout the time I work with them. I teach them that learning coping skills and techniques of self-care are ways of enhancing their life. I encourage them to develop a conscious awareness of their own needs, and not to base their life on reactive responses to a relative's illness.

Many, if not most, caregiving relatives are overwhelmed and seriously stressed. The stress may be constant or intermittent, depending on the stage of their relative's illness, their own inner resources and physical and emotional well-being, the availability of family and community support, and their ability to live with uncertainty. As Lefley (1994) has pointed out, there are no

easy answers to the painful dilemmas in which many families find themselves. There are frequently instances when what is good for the person with a psychiatric disability may not be good for the rest of the family or for individual members of the family (younger siblings, for instance, who may need to be supported). Although the most desirable intervention would be one that helps both the person with a psychiatric disability and the family, mutually beneficial solutions are not always possible (Lefley, 1994). There are times when families may have to choose between making self-protective decisions and providing care for their ill relatives. Self-protective life decisions can often contribute to guilt and ambivalence in the family.

Working Through Guilt

Excessive guilt, the “tendency to blame ourselves for things which are clearly not our fault, robs us of our self esteem and perhaps of our capacity to grow and to act” (Kushner, 1981). I spend a significant amount of class time discussing guilt. I think of guilt as a very “sticky” emotion; it tends to hang on and take energy away from the family. Guilt about making necessary self-protective decisions is often the most difficult kind of guilt for families to resolve. I find this area most challenging to work with.

Many families have to be reminded that they have a right to their own happiness. One can choose to do the best one can for one’s ill relative, but there has to be a balance. If caregiving becomes the central purpose of their lives, to the neglect of their personal growth, pleasure, and health, then the odds of their becoming physically ill and/or depressed are high, and the resulting burden on their mentally ill relatives may increase.

Caregivers who do not care for themselves are not, in the long run, going to be helpful to everyone else. I tell family members who feel that it is selfish to think of their own needs that it is selfish of them not to take care of themselves. People who neglect themselves eventually become dependent on others, and to let that happen knowingly is truly a selfish act. It is essential to keep a balance in one’s caregiving. It all starts with the self. If you are not taking care of yourself, you’re not going to be helpful to others. In addition, family members who neglect their own needs are poor role models for their ill relatives. As a young man being treated for manic depression advised

parents in one of the workshops I led: “Love yourselves, and we can learn from you to love ourselves. When we go down, don’t go all the way down with us.”

Buddhist philosophy, which makes an interesting distinction between guilt and remorse, has provided me with some helpful tools for working with family guilt. The Buddhists view guilt as being very focused on the self and one’s own pain. Guilt tends to focus our thoughts on our worthlessness: “I’m the worst person in the world. Only I do these terrible things.” This attitude is considered to be actually very “self” promoting because one’s own pain takes center stage:

When such feelings take the central role we may lose consideration of what somebody else may actually need. Remorse, by contrast, is a state of recognition. We realize that we have...done something or said something unskillful that caused pain, and we feel the pain of that recognition. But...remorse frees us to let go of the past. It leaves us with some energy to move on, resolved not to repeat our mistakes. (Salzberg, 1995)

I refer to these helpful distinctions when I tell families to let go of blaming themselves for real or imagined mistakes in the past. What’s done is done. The past is over. I tell them that they are not responsible for their family members being ill, but they are responsible for the way they respond to their illnesses.

We need to get over such questions that focus on the past and on the pain as “why did this happen to me” and ask instead the question that opens doors to the future. “Now that this has happened, what shall I do about it?” (Kushner, 1981).

Spiritual Issues

Like many people who are in pain, the families I work with are often searching for spiritual meaning in their lives. (I am using the term “spiritual” here to mean some internal, individual experience of the sacred.) I have found a real hunger from many individuals in my classes for approaches that acknowledge their spiritual needs. Families that turn to their clergy are often disappointed. Unfortunately, all too frequently the response from clergy, regardless of

denomination, has been inadequate. It is no secret within the network of family support that clergy are uninformed about and insensitive to the realities of mental illness.

Some family members report that 12-step programs like Alanon have given them substantial comfort, and several have expressed the wish that NAMI would have more of a spiritual focus. Participants in my groups regularly recommend to one another books and tapes that have helped them deal with their pain, and writings that range from Christian mysticism, Eastern religions, transpersonal psychology, and bereavement literature, to the more popular self-help offerings. Favorite authors like Levine (1982), Kornfield (1993), Kushner (1981), Borysenko (1990; 1993), Hanh (1987), Myss (1996) and others clearly speak a language that resonates with those families, searching for answers that psychotherapy has not given them. Beyond the fact that their books provide accessible and practical techniques for dealing with suffering, these authors connect families to the larger human experience, the transpersonal dimension that I use in my own work and have been addressing in this paper.

It can be argued, as did a recent New York Times op-ed article, that the United States is in the midst of a spiritual revival. We are living in a time when questions of meaning are being asked everywhere. There continues to be widespread interest in Eastern teachings, the Dalai Lama has become a culture hero, Harvard Medical School is in its third year of presenting an annual conference on "Spirituality and Healing in Medicine," meditation is being taught as a stress reduction technique and paid for by insurance companies, and some HMOs are actually investing in spiritual healing approaches. Perhaps because of this Zeitgeist I am finding families from all walks of life to be very open and receptive to new ways of thinking.

However a family chooses to deal with the stress they suffer, part of SFT is devoted to reminding them to be aware of their stress levels and to take action to deal with stress as an important component of their self-care. To combat fatigue, promote relaxation, and renew their spirits, I recommend regular physical exercise, long walks, yoga, tai chi, guided imagery tapes, therapeutic massage, and meditation. Anything done with focus, awareness, or mindfulness is a meditation, whether it is taking a walk, doing the dishes, or driving to work. When I introduce the subject of meditation to families who are unfamiliar with its benefits, I present it in terms of stress reduction

and mental self-control. Included in my instructions are simple breathing techniques and relaxation exercises that can be done independently.

The Teachers of Supported Family Training

The style in which the teachers deliver SFT is absolutely central to its effectiveness. They must be able to deal with the family's emotions with clarity and compassion. There needs to be a very conscious use of the self (Raden, 1994) by the teachers. The tone that teachers set by being open, warm, nondefensive, and accepting establishes a basic ground for this work to unfold.

The simple act of being completely present to another person is truly an act of love—no drama is required. (Salzberg, 1995)

The teacher's role in SFT has much in common with the family consultant role described by Bernheim (1982). The work is very directive. When emotional issues surface in the classes, teachers need to be comfortable offering guidance, rather than listening and reflecting back as a therapist might. It has been my experience that families benefit more at this time from practical advice, clear directions, and specific help with the service system, along with genuinely caring support, than they do from psychotherapy.

In order to help families access their feelings and be comfortable speaking about painful issues, self-disclosure by the teachers is very important in this model. Professional distancing is discouraged. I am quite open with the families that I work with about the grief and anger and frustration that I have experienced, and the ways I have had to let go in my own life. I encourage the professionals that I train to refer back to their own direct experience of pain, to keep in touch with these feelings, and to use their common sense. I ask them to consider how they would feel if their son or daughter, brother or sister, or parent or husband were diagnosed with schizophrenia or manic depression. It is essential that they empathize with the chaos that families experience when mental illness first strikes their loved ones, and not to judge their responses as "dysfunctional." Because it is sometimes necessary for professionals to transcend their own training when working in a family education model, I frequently remind them to not let their skills get in the way of helping.

Agreeing with the observation of Spaniol and colleagues (Spaniol, Zipple & Lockwood, 1993) that “professionals can help families in many ways, but not with the kind of healing that one family member gives to another” (p. 30), I acknowledge the several obvious important advantages I have as a family member/teacher. I can share and confront in ways a professional lacking personal experience cannot. When I speak from my own experience, I am a catalyst for encouraging others to speak about painful issues. When I allow my vulnerability to show and when I share my pain, I make it safe for others to do the same. But the family member/ teacher is not necessarily better than a professional who has opened her heart and who has touched her own pain, and translated it through wisdom and compassion into a tool to help others. It is the combination of skill and personal power that the teachers bring to this work that makes it possible for change to happen in a relatively short time. The best curriculum in the world cannot substitute for an uninspired or unskilled teacher. I have found that the partnership of family member and professional in a team-teaching model works best. This partnership also has the additional advantage of providing positive modeling for the families in the classes, who are encouraged in the training to see themselves as equal members of the treatment team for their ill relatives.

Conclusion

The Heart of the Work Is the Heart in the Work

The classes that I teach are ultimately about personal empowerment. They are not only about pain and loss and suffering, although working with these issues is critical. Many educational programs measure their effectiveness by tests of information retention. Although there have been outcome studies (Horgan, 1995) of Supportive Family Training indicating that families have learned the facts they need to know, I do not place significant value on this component of the training. What is much more important for families to retain, rather than specific knowledge about brain dysfunction, are the principles of self-care that I highlight throughout the course.

It is dramatic to see the change in the families from first class to last. There is a visible “lightening up” in each group. Although, naturally, there are tears, there is also a surprising amount of humor,

which is a sure sign that the participants have achieved some level of detachment from their pain. A mother in one class was greeted with appreciative laughter when she recited:

Lord no matter what may be

Give me the strength for low e.e.

There is an extraordinary spirit to the final sessions and, at the end of the course, it is quite common for participants to say that they wish it would not end. As one father observed at a last meeting, “Look at us now, do you remember how we all looked at the beginning of this course?” He was clearly referring to the sense of helplessness and despair that showed on everyone’s faces at the start of the training. At the end, there was warmth and laughter and the relief that comes from being part of a group where you feel accepted and understood.

Friendships happen in every group and social isolation significantly decreases. The act of moving out of their lonely pain and connecting to one another results in a real change in consciousness for many of the participants: they discover another way of looking at the world. I encourage “graduates” to become advocates and urge them, if they are not already members, to join NAMI. It is wonderful to see some individuals move from being isolated to being involved advocates. Advocacy is not for everyone but it can be very healing for some.

A couple who had just completed my course called for support when their 21-year-old son committed suicide in their family home. During my visit the shocked and grieving parents told me that without the class they never could have gotten through it. “We know it’s not our fault...in the middle of all this pain, at least we are not blaming ourselves.” Mixed with their anguish and despair was anger at the staff of the hospital from which their son had recently been released. They believed that their son had been misdiagnosed, overmedicated, and unnecessarily placed into restraints. They were convinced that his terror of repeating his inpatient experience contributed to his suicide. Their son had told them that, if he ever became sick again, he would rather die than go back to the hospital.

A year and a half later, the mother accompanied me to a staff training session in the hospital in which her son had been an inpatient. With a remarkable absence of blame, she spoke to the

nurses, doctors, psychiatric residents, and aides about his frightening experience in their hospital as well as her own experience of not being listened to or acknowledged by the staff there. She spoke with compassion about wanting to protect other families from the tragedy her family had experienced. Because of her skillful, non-blaming manner, the staff was able to hear her without defensiveness and to participate genuinely in a discussion of how they could best respond to the issues she raised.

I asked her what had helped her to get through this difficult time and to arrive at such an impressive level of acceptance and forgiveness. She said that she had traveled through all the stages of grief. A year after her son died she had felt herself becoming physically ill and began to search for some relief from her suffering. She found some solace from books and audiotapes (Kushner, 1981; Myss, 1996) that encouraged her to turn her attention inward. When she did that, she came to realize that her anger and bitterness were handicapping her healing process and robbing her of essential energy. Although she still mourns, she has now come to a quiet acceptance of her son's choice to end his life. This woman has gone beyond her personal heartbreak; she has healed to the point that she wants to reach out to others. She has begun the journey out of her own pain and into the world.

A meditation I use in my classes contains a line that has become a favorite of the families in SFT: it describes a heart that is broken as "having room in it for the whole universe" (Macy, 1983, p. 156).

Through suffering one learns to share the suffering of others, and through the gift of compassion, the experience of chronic illness offers protection against apathy, an indifference toward life that means, literally, "not suffering." Above all, chronic illness leads to the recognition that somehow, things work out in an examined life that is judged to be worth living (Register, 1987).

References

- Atkinson, S. (1994). Chronic grief may affect parents of children with schizophrenia. *The Menninger Letter*, 2, 1–8.
- Bernheim, K. (1982). Supportive family counseling. *Schizophrenia Bulletin*, 8, 634–640.
- Borysenko, J. (1990). *Guilt is the teacher: Love is the lesson*. New York: Warner.
- Borysenko, J. (1993). *Fire in the soul: A new psychology of spiritual optimism*. New York: Warner.
- Cassel, E. (1982). The nature of suffering and the goals of medicine. *The New England Journal of Medicine*, 306, 639–644.
- Dixon, L., Lehman, A. (1995). A. Family interventions for schizophrenia. *Schizophrenia Bulletin*, 21, 631–643.
- Doka, K. (Ed.). (1989). *Disenfranchised grief in disenfranchised grief: Recognizing hidden sorrow*. Lexington, MA: Lexington Books.
- Hanh, Thich Nhat. (1987). *The miracle of mindfulness*. Berkeley, CA: Parallax.
- Hatfield, A. (1990). *Family education in mental illness*. New York: Guilford.
- Hatfield, A. (Ed.) (1994). *Family education: Theory and practice*, in *family interventions in mental illness*. San Francisco: Jossey-Bass.
- Horgan, S. (1995). Client satisfaction with the supportive family training program. *Public Affairs Program*, Maxwell School of Citizenship and Public Affairs (pp. 1–26). Syracuse, NY: Syracuse University.
- Kornfield, J. (1993). *A path with heart*. New York: Bantam.
- Kushner, H. (1981). *When bad things happen to good people*. New York: Schocken.

- Lefley, H. (Ed.) (1987). *The family's response to mental illness in a relative, in families of the mentally ill: Meeting the challenges*. San Francisco: Jossey-Bass.
- Lefley, H. (Ed.) (1994). *Interventions with families: What have we learned? In family interventions in mental illness*. San Francisco: Jossey-Bass.
- Levine, S. (1982). *Who dies: An investigation of conscious living and conscious dying*. Garden City, NY: Anchor.
- Lindemann, E. (1945). Symptomatology and management of acute grief. *Arch. Neurology & Psychiatry*, LIII, 141–148.
- MacGregor, P. (1992). Grief, the unrecognized parental response to mental illness in a child. Unpublished manuscript.
- MacGregor, P. (1994). Grief, the unrecognized parental response to mental illness in a child. *Social Work*, 39, 160–166.
- Macy, J. (1983). *Despair and personal power in the nuclear age*. Philadelphia, PA: New Society Publishers.
- Macy, J. (1991). *World as lover, world as self*. Berkeley, CA: Parallax Press.
- McFarlane, W., Dunne, E., Lukens, E., et al. (1993). From research to clinical practice: Dissemination of New York State's family psychoeducation project. *Hospital and Community Psychiatry*, 44, 265–269.
- Myss, Caroline. (1996). *Anatomy of the spirit*. New York: Crown.
- Raden, B. (1994). Use of self in psychotherapy. *Bulletin of the Group Relations Training Association* (p. 7–9). Evanston, IL.
- Register, C. (1987). *Living with chronic illness: Days of patience and passion*. New York: Free Press.
- Salzberg, S. (1994). *Loving kindness: The revolutionary art of happiness*. Boston: Shambhala.

- Solomon, P. (1996). Moving from psychoeducation to family education for families of adults with serious mental illness. *Psychiatric Services*, 47, 1364–1370.
- Spaniol, L., Zipple, A., & Lockwood, D. (1993). The role of the family in psychiatric rehabilitation. *Innovations & Research*, 2, 27–32.
- Terkelsen, K. (1983). Schizophrenia and the family: Adverse effects of family therapy. *Family Process*, 22, 199–200.
- Young, S. (1994). Purpose and method of vipassana meditation. *The Humanistic Psychologist*, 22, 53–61.